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COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

NINETY-EIGHTH CONGRESS

SECOND SESSION

ON

S. 2053

FEBRUARY 27, 1984

Printed for the use of the Committee on Finance

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THE COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983

MONDAY, FEBRUARY 27, 1984

U.S. SENATE,
SUBCOMMITTEE ON HEALTH,
COMMITTEE ON FINANCE,
Washington, D.C.

The subcommittee met, pursuant to notice, at 1:33 p.m., in room SD-215, Dirksen Senate Office Building, Hon. David Durenberger (chairman) presiding.

Present: Senators Durenberger and Dole.

Also present: Danforth, Chafee, Pell, and Exon.

[The press release announcing the hearing, the prepared statements of Senators Dole and Chafee, and background information on S. 2053, follow:]

[Press Release No. 84-106]

THE SENATE FINANCE SUBCOMMITTEE ON HEALTH SCHEDULES HEARING ON COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983, S. 2053

Senator Dave Durenberger (R., Minn.), chairman of the Subcommittee on Health of the Senate Committee on Finance, announced today that the Subcommittee will hold a hearing on S. 2053, the Community and Family Living Amendments of 1983. The hearing is the third in a series of hearings on long-term care.

The hearing will be held on Monday, February 27, 1984, beginning at 1:30 p.m. in Room SD-215 of the Dirksen Senate Office Building.

In announcing the hearing, Senator Durenberger noted that "federally supported long-term care programs for the elderly and disabled emphasize costly institutional care. As part of our ongoing hearings on long-term care, the subcommittee is interested in the development of an integrated long-term care delivery system which provides an appropriate level of care, in an appropriate setting, on a cost-effective basis. The provisions of S. 2053 provide a basis on which to begin our examination of ways to provide for the long-term care needs of the Nation's disabled population. S. 2053 would seek to provide more individualized services for the severely disabled by shifting federal medicaid funds from institution for the disabled, primarily intermediate care facilities [ICF's] and ICF's for the mentally retarded, to community-based settings."

Senator Durenberger stated that the subcommittee is interested in hearing from the administration, the States, providers, and consumers. The subcommittee is particularly interested in comments on the possible benefits to be derived for the disabled and the medicaid program as the result of the proposed shift to community-based care; the feasibility and obstacles to providing such care; and the experience available from existing community-based facilities for the disabled.

OPENING STATEMENT OF SENATOR BOB DOLE

I am pleased to have the opportunity today to participate with my colleagues in this hearing on S. 2053, "The Community And Family Living Amendments Act." I know of the importance of this issue and of the merit of the arguments both sides bring to the proposal.

A few weeks ago, while in Kansas, I had the opportunity to meet with individuals who were interested in this proposed legislation. At that time, I heard both support for the concept of deinstitutionalization as embodied in the bill, and reservations about its likely impact on certain institutions and individuals.

The bill would involve a fundamental shift in our Medicaid reimbursement policies affecting mentally retarded persons. Over a 10- to 15-year period, medicaid funding to large institutions serving the mentally retarded would be phased out and redirected to small community-based settings. Any such fundamental change requires careful consideration. I welcome the opportunity to hear in more detail from our witnesses today their views regarding S. 2053.

STATEMENT BY

SENATOR JOHN H. CHAFEE

FEBRUARY 27, 1984

HEARINGS ON S. 2053

SUBCOMMITTEE ON HEALTH

MR. CHAIRMAN, I WOULD LIKE TO THANK ALL OF THOSE WHO HAVE COME HERE TODAY TO PARTICIPATE IN THESE HEARINGS. MOST NOTABLY, I THANK CHRIS CRADDY, WHO LIVED FOR MANY YEARS IN A LARGE INSTITUTION IN MY OWN HOME STATE OF RHODE ISLAND, AND NOW LIVES IN A COMMUNITY-BASED HOME. CHRIS WILL SHARE WITH US HER PERSONAL FEELINGS ABOUT LIFE IN THIS VERY DIFFERENT SETTING.

WE WILL ALSO HEAR FROM EXPERTS WHO ARE INVOLVED IN THE CARE OF THE SEVERELY DISABLED AND RETARDED BOTH IN LARGE INSTITUTIONS AND COMMUNITY-BASED HOMES, AS WELL AS SEVERAL PARENTS OF RETARDED OR DISABLED INDIVIDUALS.

SOME TIME AGO, I READ SOMETHING THAT I WOULD LIKE TO SHARE WITH YOU TODAY:

THE SEVEN STEPS TO STAGNATION:

1. WE'VE NEVER DONE IT THAT WAY

2. We're not ready for that yet
3. We're doing all right without it
4. We tried it once and it didn't work out
5. It costs too much
6. That's not our responsibility
7. It won't work

This bill gives us the opportunity to take positive actions on behalf of those who most need our help. These hearings provide us with a long overdue forum in which we can closely scrutinize the current system of care and determine how it can be improved to benefit those who need it most.

This legislation is highly controversial and evokes tremendous emotion. It is crucial to bear in mind that we all share a common purpose -- to provide the best possible care to our retarded and disabled citizens who are not able to care for themselves. Our goal today is to determine how this purpose can best be accomplished.

SINCE I INTRODUCED THIS BILL LAST NOVEMBER, I HAVE RECEIVED QUESTIONS ABOUT THE STABILITY OF GROUP HOMES, THE ADVISABILITY OF THE 10-15 YEAR SHIFT OF FEDERAL FUNDS TO COMMUNITY PROGRAMS FORM LARGER FACILITIES, THE ELIGIBILITY REQUIREMENTS OF PATIENTS, THE COST, AND MOST IMPORTANT, HOW THE STATES WILL BE ABLE TO DEVELOP VIABLE COMMUNITY-BASED FACILITIES THAT PROVIDE A HIGH QUALITY OF CARE. I HOPE THAT WE CAN ADDRESS ALL OF THESE QUESTIONS TODAY TO THE SATISFACTION OF EVERYONE WHO HAS EXPRESSED SUCH HEARTFELT INTEREST AND CONCERN.

WE ALL HAVE A TENDENCY TO FEAR THE UNKNOWN. THAT IS WHY WE ARE HERE TODAY -- TO EXAMINE THIS IDEA OF GROUP HOMES, WHICH IS NEW, AND DIFFERENT AND UNKNOWN TO MOST OF US. WE ARE HERE TO LEARN FROM THOSE WHO WILL TESTIFY -- TO LEARN FROM THEIR KNOWLEDGE AND THEIR EXPERIENCE.

WE SHOULD NOT DENY OUR RETARDED AND DISABLED CITIZENS THE OPPORTUNITY TO GROW AND PARTICIPATE IN THE COMMUNITY BECAUSE OF OUR OWN INABILITY TO GRAPPLE WITH THE UNKNOWN. CONGRESS AND OUR NATION HAVE ALWAYS STRIVED TO BETTER THE CURRENT SITUATION. HOW CAN WE ASK ANY LESS FOR THESE PATIENTS OF INSTITUTIONS.

Community and Family Living Amendments Act of 1983

S. 2053

Prepared by the Staff for the Use of
the Committee on Finance
United States Senate

February 1984

I. Key Points

- In 1971, Congress amended Title XIX, Medicaid, to permit reimbursement for services provided in intermediate care facilities (ICFs). An ICF refers to any facility of four or more beds in which health-related services are provided to individuals who do not require the degree of care or treatment that a hospital or skilled-nursing facility is designed to provide. In addition to facilities serving the general population, the amendments also permitted public facilities serving the mentally retarded to be certified as ICFs. Since then, most States have amended their Medicaid plans to include so-called intermediate care facilities for the mentally retarded (ICFs/MR).

- By 1982, total (Federal/State) Medicaid outlays for intermediate care facilities totalled $8.5 billion: $4 billion to provide services to 645,000 elderly recipients, approximately $1 billion to provide services to 121,000 non-elderly, physically disabled persons, and $3.5 billion to provide services for 154,000 mentally retarded persons.

- Medicaid requires that intermediate care services be provided on-site, which leads to a so-called institutional bias. Home-based intermediate care, except under certain program waiver provisions, is not financed by medicaid. Facilities providing institutional care for mentally retarded (MR) or developmentally disabled (DD) persons currently range in size from 16 to 2,000 beds, although most institutionalized MR/DD persons are in State administered public facilities of over 300 beds.

- S. 2053 would modify these provisions of Title XIX so as to divert funds from intermediate care facilities to small community-based organizations providing intermediate care services for the non-elderly, severely, physically and/or developmentally disabled Medicaid-eligible recipient.

- A community-based facility as defined in S. 2053 is small (no more than approximately 9 beds), located within a residential neighborhood, and accessible to neighborhood services.

- The population likely to be most immediately affected by S. 2053 is the MR/DD population now residing in large (usually State-operated) facilities certified as ICFs-MR.

II. Background

Notwithstanding medicaid's financing bias, during the 1970's a growing number of mentally retarded individuals moved from facilities into community-based care arrangements, and a growing number of families chose community-based care over institutional placement for their mentally retarded family members.

This trend can be explained in various ways. In part it appears to be the result of a growing belief by some that even the most severely disabled person has the potential for growth and development, and an accompanying belief that this development can best be fostered in a "normalizing" environment, that is, an environment which approximates, as closely as possible, normal family and community living. Adherents of this view have often used the courts to force deinstitutionalization. Alternatively, this trend has been explained by cost-cutting measures instituted by the States.

Whatever the cause, the trend is clear. The population of public institutions decreased 36 percent between 1971 (when there were 187,546 residents) and 1982 (when there were 119,335 residents). As the less severely disabled persons were either transferred from institutions to community settings over the past decade or remained within the community, those continuing to live in public institutions tended to be the most severely handicapped persons, often with multiple handicaps. In 1982, 81 percent of residents of public institutions were profoundly or severely retarded and 19 percent were moderately to mildly retarded. Of those remaining in institutions, 43 percent have mutiple handicaps. In addition, the percentage of those with an emotional handicap nearly tripled between 1976 and 1982. Thirty-six percent of the institutionalized MR population have an emotional handicap.

As MR/DD persons are transferred out of institutions and into community living facilities, many such persons are placed in group homes in residential neighborhoods or in group living arrangements in multi-family buildings.

A 1982 study showed that there were 63,703 MR/DD persons living in 13,862 community facilities of 15 beds or fewer. This represents a 35 percent increase in the number of such persons living in such facilities since 1977.

The GAO recently completed a report which presents information on the issues encountered and the funding sources used in the establishment and operation of group homes for mentally disabled persons. The GAO found that zoning and other land-use policies generally were not a major hindrance in the establishment of group homes.

Funding was cited in the GAO survey as a greater problem than zoning or other land-use requirements in establishing and operating group homes. Thirty-eight percent of the group home sponsors reported experiencing a high degree of difficulty in obtaining funds to establish or operate their group home. Start-up costs, operation costs and Federal funding were cited as the major funding problems. The GAO found that funding and sponsors for group homes for the mentally retarded were as follows:

Founders and Sponsors:

- o 65 percent had private non-profit sponsors.
- o 8 percent of the homes were proprietorships.
- o Most other group homes were sponsored by the public sector.

Start-up Funds:

- o 39 percent of the homes received private funds.
- o 55 percent of the homes received State funds.
- o 25 percent of the homes received local funds.
- o 13 percent of the homes received Federal funds, other than HUD Section 202 loans. Two percent used HUD 202 funds.
- o Charities and community fund drives also provided start-up funds.

Operating Funds:

- o 78 percent of the homes used clients' Supplemental Security Income (SSI) funds.
- o 65 percent of the homes received State funds.
- o 13 percent of the homes received ICF/MR funds.
- o Other operating fund sources included personal income, title XX (social services), local government funds, private funds, community fund drives and donations from charitable organizations.

According to the GAO, 26 percent of the group home sponsors experienced great difficulty locating suitable sites or facilities. These problems included finding accomodations with adequate bed and bath facilities, favorable landlord attitudes toward leasing, a safe neighborhood, and proximity to public transportation and medical and social services.

Although patients increasingly are being served in community settings, public monies have not followed them. A large share of public funding for out-of-home care for the severly disabled comes from the Federal/State Medicaid program, 75 percent of which is directed toward institutions rather than community-based programs. S. 2053 provides for a gradual shifting of Federal funds from large institutions to community-and-family-based integrated settings. Those individuals requiring highly structured 24-hour care, including medical attention, would be provided with this care in facilities within the community. Those needing fewer services -- whether living at home, in foster care, in a group home, or in an apartment -- would also receive the appropriate medical attention and developmental services.

Various terms are used to refer to the severely disabled, primarily mentally retarded population which may receive publicly funded services. The Medicaid program, authorized under Title XIX of the Social Security Act, provides Federal funds to help support services for "mentally retarded or persons with related conditions" who require institutional care. S. 2053, which is the focus of this paper, provides a definition for "severely disabled individual" which is based on the definition of "developmental disability" under the Developmental Disabilities Assistance and Bill of Rights Act, P.L. 91-517, as amended.

This paper uses the term "mentally retarded and other developmentally disabled" (MR/DD) persons, a term commonly used in the field, to generally encompass the population referred to in the above documents.

III. Current Law

Federal funds to help support services for institutionalized MR/DD persons are authorized under the Medicaid program, Title XIX of the Social Security Act. The MR/DD population requiring 24-hour care may receive such services in several types of Federally funded programs. To receive Federal funds, programs must meet certification standards established under the Medicaid program. There are three types of Medicaid-certified providers in which MR/DD persons are provided care: 1) intermediate care facilities for the mentally retarded (ICFs/MR), 2) intermediate care facilities (ICFs) and 3) skilled nursing facilities (SNFs).

1. Most institutionalized MR/DD persons receive services in ICFs/MR. These facilities range in size from 4 to 2,000 beds, but the great majority of residents, over 90 percent, are in facilities of 16 beds or more. Facilities with under 200 beds are largely administered by the private sector, and those over 200 beds are most likely public institutions.

Federal regulations providing standards for ICFs/MR are intended to assure a safe and therapeutic environment and include provisions for adequate staffing, health and safety requirements and minimum specifications for individual space and privacy. Residents of ICFs/MRs may receive rehabilitative services and an individual plan of care is required for each resident. The plan must include services necessary to enable residents to attain or maintain optimal physical, intellectual, social and vocational functioning.

2. Some MR/DD persons are served in nursing care homes certified under Medicaid as ICFs. These facilities provide health-related care and are not required to provide the rehabilitation services authorized in the ICF/MR program. Approximately 30,000 MR persons are currently served in ICFs, according to an unofficial estimate of the Congressional Budget Office (CBO).

3. SNFs serve some mentally retarded persons who require a greater degree of health care than is provided in ICFs. Approximately 13,500 MR persons are served in SNFs, according to CBO.

The three services mentioned above are funded through open-ended entitlements. That is, States are not limited in the amount of Federal funds they may receive as long as they meet standards and provide the required matching funds. The Federal share for these services ranges from 50 to 83 percent depending on the State per capita income. The average Federal share for these services is 53 percent. Skilled nursing facility services must be included in Medicaid State plans while services in ICFs are optional.

Congress extended to States significantly greater flexibility in developing alternatives to institutionalization by including Section 2176 in the Omnibus Reconciliation Act of 1981 (ORA). This section granted the Secretary of the Department of Health and Human Services the authority to waive certain medicaid requirements to allow States to set up home- and community-based long-term care delivery systems for medicaid-eligible individuals who were at risk of institutionalization. The flexibility to modify certain program eligibility requirements which promoted institutionalization was provided to States, as was the ability to provide a broad range of community-based services not normally covered under medicaid. The States' response to this statutory provision is described later in this report.

IV. S. 2053: Description and Issues

A. Description

S. 2053 modifies Title XIX, Medicaid, to limit reimbursement for services to the severely disabled to those rendered in community or family-living facilities. Funds would be diverted away from large State institutions (that currently are ICF certified) and nursing homes certified as ICFs. An exception would allow temporary institutionalization (no more than two years per individual) under certain conditions.

Important definitions in S. 2053:

- "severely disabled individuals": individuals with a disability attributable to a developmental or physical impairment (or combination), that is manifested before age 50, is likely to continue indefinitely, and results in substantial functional limitation. (The definition specifically excludes persons between the ages of 21 and 65 who have a primary diagnosis of mental illness.)

- "community or family living facility": refers to natural, adoptive, foster, and group homes whose size does not exceed three times the average family household size for the area, whose location is within residential neighborhoods, and which meet certain staffing, service, safety, and sanitation standards.

- reimbursible "care and services": includes home or community-based health care, comprehensive services for independent living as defined in the Rehabilitation Act of 1973 (e.g., personal aides or attendants, domestic assistance, family support services, respite care, case management, habilitation and rehabilitation services), specialized vocational services, room and board, and administrative expenses.

Under the provisions proposed in S. 2053, all large Medicaid-funded ICFs would have 10 years to phase out their programs (15 years for facilities that opened after January 1, 1979 and contain 16 to 75 residents). Facilities of 15 or fewer residents that were in operation on the date of the bill's enactment would not be affected by this provision.

The bill contains a provision providing for a 5 percent increase in the Federal Medicaid matching rate for each disabled person moved from an institution to a community setting. The higher matching rate would continue for 5 years following the individual's return to the community.

The bill would also provide for an expansion of eligibility at the option of the State. Under the provisions of S. 2053, a State may, use Medicaid funding for services to severely disabled individuals under age 18 (whose families were not eligible for medicaid) if such person or his family spent at least 5 percent of adjusted gross income for the provision of care and services to such persons.

The bill also includes provisions for independent evaluations, individualized service plans, periodic reviews, program standards, fiscal audit procedures, and sanctions for noncompliance.

B. Issues

The introduction of S. 2053 has intensified debate regarding the appropriateness of institutional care, family-scale living and other levels of service and care for the MR/DD population. While all persons interested in care to this population favor quality residential services for MR/DD persons, there is considerable disparity regarding the types of care considered most appropriate. Some professionals, parents of disabled persons and other advocates feel that a continuum of residential alternatives, including institutional care, provided in ICFs/MR should continue to be available. These individuals contend that these facilities are cost-effective and meet the various needs of MR/DD persons.

Alternatively, advocates of S. 2053, who also include professionals, parents of disabled persons, and other interested and informed persons, feel that family-scale living arrangements provide a superior service setting for all the needs of MR/DD persons by providing personalized care in a more normalized, cost-effective setting.

The major issues of the debate are centered around the following questions:

- Is community care better than institutional care in all cases?
- Can the medically fragile MR/DD person who requires 24-hour nursing care and frequent physician services be effectively served in small community living facilities?
- Should all institutions be phased out even if they appear to provide good care and families are satisfied with the care provided?
- What economic hardship will the closing of facilities have on the communities in which they are located and on the current employees?
- Does the bill provide strong enough Federal standards to assure quality of care and safety in widely disbursed facilities each serving a small number of clients?

- Can not the Section 2176 medicaid waiver provision be used to accomplish the goals of S. 2053 without new legislative authority?

- Are communities ready to receive MR/DD persons in large numbers from institutions?

- Many States, in an effort to upgrade their institutions, have floated long-term bonds for capital improvements. If S. 2053 is implemented, how can States manage this long-term debt? Conversely, from where will the capital funds come to build or renovate structures within the community?

And finally, how costly will S. 2053 be to implement? In the short term, a dual system will be in operation. Institutions will continue to operate during the phase-out period at the same time that institutions, a direct dollar for dollar transfer will not be possible. Also, the scope of services is broader in S. 2053 than is currently defined under Medicaid regulations for ICFs and ICFs/MR, and there is a possibility of an expanded caseload under S. 2053.

Informal estimates of the number of MR/DD persons who could be eligible for Medicaid services who currently are not receiving such services range from 625,000 to 2 million. It could be argued that MR/DD persons eligible for Medicaid services should have access to such services regardless of where they reside. If such persons seek services under S. 2053, total medicaid expenditures could increase.

V. Federal and State Initiatives

Many of the recent Federal activities regarding long-term care policy have been directed toward liberalizing Medicaid funding so as to allow States more flexibility to develop community-based services. One example is the Medicaid Home and Community-Based Waiver Initiative (P.L. 97-35 Section 2176) which has resulted, to date, in the approval of 45 program waivers, 28 of which deal with the developmentally disabled population, and the rest of which address the needs of the physically disabled, both elderly and non-elderly. Most of the waiver projects, however, unlike S. 2053, are directed more toward preventing premature or unnecessary institutionalization through the provision of alternative community-based services than toward active deinstitutionalization efforts. However, those waiver projects that primarily affect the MR/DD population, like the one granted the State of Maryland are directed toward furnishing case management, residential habilitation, day care and transportation services to MR/DD clients who are presently institutionalized in ICF/MR facilities but will be relocated to community-based facilities. Results from this and other waiver projects are not yet available but eventually may provide data on the feasibility of and costs associated with community-based services for the severely disabled.

In some States, both judicial mandate and State-sponsored legislation have accelerated the transfer of disabled persons (especially mentally and developmentally disabled) from State facilities to the community. Deinstitutionlization of the mentally retarded has occurred in Pennsylvania (Pennhurst State School), New York (Willowbrook), and Nebraska (Beatrice State Developmental Center), to name just a few of the more well-known examples. There are currently dozens of court cases underway in a total of 15 or 20 States. These cases generally have arisen from documented abuses within institutions.

In 1980, the Civil Rights of Institutionalized Persons Act, P.L. 96-247, gave the Attorney General explicit authority to initiate and intervene in litigation involving the constitutional rights of institutionalized persons. Since the enactment of the statute, the Attorney General has undertaken 41 investigations of institutions, 18 of which involved mental health or mental retardation facilities.

The following States have recently announced plans to close one or more State institutions for; MR/DD persons: Maryland, Minnesota, Florida, Michigan, Illnois, Pennsylvania, Vermont, and Montana.

These State efforts at deinstitutionalization have been followed closely although evaluations of their results have been inconclusive. Some researchers have found lower costs for community alternatives while others are unable to find a consistent difference in costs in favor of community programs or institutional programs. Many of the differences in cost study findings have been attributed to poorly controlled cost identification and finding procedures. In addition, few studies have controlled or even accounted for differences in client dysfunction.

The most recent comparative analysis of the costs of residential and day services within institutional and community settings comes out of the 4th year report of a longitudinal study of the court-ordered deinstitutionalization of residents of the Pennhurst Center in Pennsylvania. On average, community programs were found to cost less per client day than Pennhurst Center programs, although the community programs showed a much larger range in cost per client day, $19.64 to $252.66, than did the Pennhurst programs, $80.26 to $211.88.

Most of these differences are explained by personnel costs. Pennhurst Center staff are paid more and enjoy a more generous fringe benefit package than do their counterparts in community programs. Since between 70 and 80 percent of program costs relate to personnel, the relative prices paid for these services are a major component of the cost of programs. This finding is significant in light of the provision in S. 2053 which mandates the protection of employees who would be affected by the transfer of severely disabled individuals to community or family living facilities. Included within these protections would be the preservation of the rights and benefits that these employees now enjoy, including reemployment in the community facilities and the provision for training or retraining.

In addition to cost studies, some attention has been given to the effects of deinstitutionalization on client functioning. In a comparison of those Pennhurst residents who were placed in community settings with those who remained within the facility, the deinstitutionalized clients showed gains in independent functioning and developmental growth. In another study that evaluated a Statewide program of deinstitutionalization in Montana, favorable changes in behavior also were observed when clients left institutional settings.

However, not all clients that are deinstitutionalized remain so. When examining the ratio of readmitted clients to the population of institutionalized clients, there appears to be an increase in readmission over the past several years. In 1964, the ratio of readmitted to institutionalized persons was 1 to 113.6; the 1980 ratio was 1 to 25.6. Reasons cited for readmission from community placement are: community rejection, 13 percent; lack of community services, 52 percent; family inability to cope, 49 percent; and, failure to adjust, 49 percent. Obviously, these reasons are not mutually exclusive.

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S. 2053 AND THE TRANSFER OF MENTALLY RETARDED PERSONS FROM LARGE INSTITUTIONS TO SMALL COMMUNITY LIVING ARRANGEMENTS

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S. 2053 AND THE TRANSFER OF MENTALLY RETARDED PERSONS FROM LARGE INSTITUTIONS TO SMALL COMMUNITY LIVING ARRANGEMENTS

INTRODUCTION

For the past 20 years there has been considerable concern about the quality of care in some of the large residential institutions which provide care for persons with mental retardation and related disabilities. For the purposes of this paper, "institution" means a residential facility of 16 or more beds which provides 24-hour care seven days a week. Most institutionalized retarded persons reside in institutions of 300 beds or more. The Federal Government helps support services in those institutions which meet, or have a plan to meet, Federal standards of care. However, recent judicial and legislative actions indicate that abuses and other problems remain in some institutions. In an effort to improve living conditions and provide a more normal environment for such disabled persons, many of those who are less severely handicapped have been moved into smaller facilities in community settings. Some profoundly retarded and/or multiply handicapped persons have also been moved into smaller facilities.

A legislative proposal has been introduced which would change the locus of care for institutionalized disabled persons. Some professionals and parents, primarily the Association for Retarded Citizens, prepared the proposal which has been introduced as S. 2053. S. 2053 would gradually transfer Federal funding out of large institutions and into family-scale living arrangements so that disabled persons currently served in institutions may live in households and receive services in a more normal community setting. Under the bill, Federal funds could be used in larger facilities only if the period of institutionalization did not exceed two years.

S. 2053 is very controversial. Advocates of the proposal feel that institutions are detrimental to the development of disabled persons and that the funding for large institutions should be eliminated so that these funds can be used in small, neighborhood facilities where training and more normal living patterns can help disabled persons live a more independent life. Those opposed to the bill, also professionals and families with concern for these disabled persons, feel that some disabled persons need long-term institutional services, that substandard institutional services should be improved rather than abolished, and that a choice of institutional and communtiy services should be made available to meet the needs of disabled persons and the wishes of their families. Advocates for the bill claim that a dual system of institutional and communtiy services would be prohibitively expensive.

This paper provides data on the number of institutionalized mentally retarded persons and their disabilities. (This paper addresses issues of the mentally retarded and persons with related conditions, not the mentally ill.) Federal funding sources for this population are summarized, existing community-based services are discussed, and cost findings of the various service settings are presented. The provisions of S. 2053 are explained and a discussion of the bill sets forth the major positions taken by those supporting the bill and by those who oppose the bill or would like to see it amended.

I. BACKGROUND

Over the past 100 years many large institutions were built to provide care for mentally retarded persons. These institutions, which frequently served many hundreds of residents, provided 24-hour maintenance and, in some facilities, therapeutic care. The institutions generally were built in rural areas not adjacent to towns or cities, and for this reason, normal community involvement of the institution residents was not generally possible. Prior to the 1950s, such institutional services were virtually the only available source of services for persons with mental retardation, and many families were encouraged by their physicians to institutionalize severely handicapped newborns at birth. A General Accounting Office (GAO) report characterizes institutional care as follows:

> Until the 1960s, mentally disabled persons who could not afford private care had to rely primarily on public institutions for their care. Conditions in these institutions generally were harsh. Treatment programs were limited; living quarters were crowded; few recreational or social activities were available; and individual privacy was lacking. In general, the institutions served as custodial settings, often with unpleasant conditions, and many people remained institutionalized for years. 1/

In the 1930s parents of retarded children began to organize and to encourage the development of community services so that their handicapped children could receive specialized developmental services while living at home. These parents also worked to bring about improvements in institutions. This parents'

1/ U.S. General Accounting Office. Summary of a Report—Returning the Mentally Disabled to the Community: Government Needs to do More; Report to the Congress by the Comptroller General of the United States, HRD-76-152A, Jan. 7, 1977, Washington. p. 1.

group is known as the Association for Retarded Citizens. The movement to improve community services and institutional conditions for mentally retarded persons was supported by President Kennedy who appointed a panel to study the issue and report to the President. The panel recommended that institutional care be restricted to those retarded persons whose specific needs can be met best by this type of service. The panel further recommended that local communities, in cooperation with Federal and State agencies, undertake the development of community services for the retarded. 2/ Abuses and neglect of retarded institutionalized persons were reported in the press, and during the 1960s and the 1970s efforts were made nationwide to improve conditions in institutions, expand alternatives to institutionalization, and to remove residents from institutional to community settings. This became known as the deinstitutionalization or normalization movement.

In 1975, the Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103), included provisions intended to improve services to mentally retarded and other disabled persons in institutions. This law required that States submit a plan to eliminate inappropriate placement in institutions and improve the quality of institutional care. State plans were also to support the establishment of community programs as alternatives to institutionalization.

Also in 1975, the Education for All Handicapped Children Act, P.L. 94-142, required States to provide educational and supportive services in the least restrictive environment for all handicapped children. 3/

2/ The President's Panel on Mental Retardation. A Proposed Program for National Action to Combat Mental Retardation. Report to the President, Oct. 1962.

3/ For additional background information see: Paul, James L., Stedman, Donald J., and Neufeld, G. Ronald, eds. Deinstitutionalization: Programs and Policy Development. Syracuse, University Press. 1977.

II. RESIDENTIAL INSTITUTIONS FOR MENTALLY RETARDED AND OTHER DEVELOPMENTALLY DISABLED PERSONS

A. Background Data

A 1982 survey indicated that there wre 243,669 retarded persons served in some type of licensed care facility: public or private institutions, nursing homes, supervised group or individual living arrangement, foster care, and boarding homes. (This number does not include disabled persons living with their families or living in non-licensed facilities.) Table 1 shows the number of persons served by size of facility and the number of facilities serving each age cohort.

TABLE 1. Number of Persons with Mental Retardation or Related Conditions Served in State Licensed Residential Facility as of June 30, 1982

Number of Beds in Facility	Number of Persons Served	Number of Facilities
1-6 a/	33,188	10,469
7-15	30,515	3,393
16-63	25,691	1,098
64-299	45,709	495
300 plus	108,566	178
TOTAL	243,669	15,633

a/ Facilities of six beds or fewer are mostly foster care arrangements.

Source: Charles Lakin, Ph.D, Center for Residential and Community Services, University of Minnesota. From 1982 National Survey of Residential Facilities for Mentally Retarded People. (Survey supported by a grant from the Health Care Financing Administration.)

Large institutions originally built to provide 24-hour care to mentally retarded persons became, in many places, the only available residential facility for persons with severe cerebral palsy, unconrolled epilepsy, autism and certain other severe, chronic or multiply handicapping conditions. Facilities providing institutional care for these mentally retarded and other developmentally disabled (MR/DD) persons currently range in size from 16 to 2,000 beds, although most institutionalized MR/DD persons are in State-administered public facilities of over 300 beds. 4/

B. Deinstitutionalization

Over the past decade there has been a nationwide effort to move the less severely disabled persons out of large public institutions and into small community-based facilities. As a result of this effort, the population of public institutions decreased 36 percent between 1971 and 1982. 5/

As disabled persons were transferred from institutions to community settings over the past decade, those remaining in public institutions tended to be the most severely handicapped persons. In 1982, 57.2 percent of the residents of public institutions were profoundly retarded, 23.8 percent were severely retarded, 12.3 percent were moderately retarded and 6.1 percent were mildly retarded. As the less severely handicapped persons were transferred to the community, the percentage of institutionalized retarded persons with mutiple handicaps has increased: 12 percent are blind; 6 percent are deaf; 41 percent have epilepsy; 21 percent have cerebral palsy; and 36 percent have an emotional

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4/ See Appendix A for a discussion of terms used to designate client population. See Appendix B for a State-by-State table of MR/DD persons in various types of residential care.

5/ See Appendix C.

handicap. In 1976, 34.4 percent of the residents of public residential facilities were multiply handicapped; this number had increased to 43.1 percent by 1982. The percentage of those with an emotional handicap nearly tripled during that period from 13.3 to 36.0 percent. In summary, of those residents remaining in public institutions, 81 percent are severely or profoundly retarded, 43 percent are multiply handicapped, and 36 percent have an emotional handicap.

The adaptive behavior of these institutionalized residents is characterized as follows:

o 29 percent cannot walk without assistance;

o 61 percent cannot dress without assistance;

o 40 percent cannot eat without assistance;

o 28 percent cannot understand the spoke word;

o 55 percent cannot communicate verbally; and

o 40 percent are not toilet-trained.

Although total institution populations have decreased 21 percent since 1976, there was a 15 percent increase in the institutionalized population age 22 or older. This indicates a decrease in the admissions of MR/DD children to institutions. Services provided under the Education for All Handicapped Children Act, P.L. 94-142, are generally considered the major reason for the decrease in the number of MR/DD persons under age 22 who have been institutionalized since 1976.

III. FEDERAL SUPPORT FOR INSTITUTIONALIZED MR/DD PERSONS

Federal funds to help support services for institutionalized MR/DD persons are authorized under the Medicaid program, title XIX of the Social Security Act. The MR/DD population requiring 24-hour care may receive such services in several types of federally-funded institutional settings. To receive Federal funds, these facilities must meet certification standards established under the Medicaid program. There are three types of Medicaid-certified facilities in which MR/DD persons are provided care: intermediate care facilities for the mentally retarded (ICF/MR), intermediate care facilities (ICF) and skilled nursing facilities (SNF).

1. Most institutionalized MR/DD persons receive services in ICFs/MR, a program authorized in 1971. An institution is eligible for ICF/MR payments if the primary purpose of such institution is to provide health or rehabilitative services for mentally retarded individuals and if the institution meets Federal standards. Institutionalized persons for whom payment is made must receive active treatment under the program. As of June 30, 1982, 138,738 MR/DD persons were residents of a Medicaid-certified ICF/MR. 6/ These facilities range in size from 4 to 2,000 beds, but the great majority of these residents, over 90 percent, are in facilities of 16 beds or more. Facilities with under 200 beds are largely administered by the private sector, and those over 200 beds are usually public institutions. Federal regulations providing standards for ICFs/MR are intended to assure a safe and therapeutic environment and include provisions for adequate staffing, health and safety requirements and minimum specifications for individual space and privacy. 7/ An individual plan of care

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6/ February 9, 1984, telephone conversation with Charles Lakin, Ph.D, Center for Residential and Community Services, University of Minnesota. Data from 1982 National Census of Residential Facilities for Mentally Retarded People.

7/ 42 CRF 442 subpart G, promulgated in 1974.

is required for each resident. The plan must include services necessary to enable residents to attain or maintain optimal physical, intellectual, social and vocational functioning.

2. Some MR/DD persons are served in nursing care homes certified under Medicaid as ICFs. These facilities provide health-related care and are not required to provide the habilitation services authorized in the ICF/MR program. The Health Care Financing Administration has issued a statement saying that the acceptance of MR/DD persons in ICFs and SNFs is generally inappropriate, but service needs of such persons currently in such facilities are to be met. Approximately 30,000 MR persons are currently served in ICFs, according to an unofficial estimate of the Congressional Budget Office (CBO). 8/

3. SNFs serve some MR/DD persons who require a greater degree of health care than is provided in ICFs. Approximately 13,500 MR persons are served in SNFs, according to the CBO memorandum.

The three services mentioned above are funded through open-ended entitlements for eligible persons. That is, States are not limited in the amount of Federal funds they may receive for services provided to eligible individuals as long as they met standards and provide the required matching funds. The ICFs and ICFs/MR may be included in Medicaid State plans; SNFs are required to be included for eligible persons over age 21. The Federal share for these services ranges from 50 to 83 percent depending on the State per capita income. The average Federal share for these services is 53 percent.

Of the approximately 244,000 MR/DD persons in State-licensed residential facilities, about 182,000 are receiving Medicaid-supported services. The remainder are in foster care, group homes and public and private institutions which are supported with State funds, private donations, fees paid by families, and income maintenance support paid to MR/DD persons.

8/ Memorandum to Christine Ferguson of Senator Chafee's staff from Diane Burnside of CBO, Dec. 12, 1983. The memorandum represents a summary of the cost analysis of S. 2053, Community and Family Living Amendments of 1983, which was introduced by Senator Chafee on Nov. 4, 1983. The data in this memorandum are preliminary staff estimates and are not to be considered official CBO estimates.

IV. OVERVIEW OF RECENT REGULATORY, JUDICIAL AND LEGISLATIVE ACTIONS TO REDUCE ABUSES OF INSTITUTIONALIZED MR/DD PERSONS

Litigation and legislation has focused public attention on abuses and deficiencies in institutions. There is general agreement, however, that the ICF/MR regulations published in 1974 have been instrumental in significantly improving conditions in institutions. According to many experts in the field, there are many institutions which provide appropriate services in safe, humane environments. The following discussion is not intended to imply that abuses exist in all institutions.

A. ICF/MR Standards

The promulgation of ICF/MR regulations in 1974 was an effort to establish and ensure active treatment and a safe environment in institutions for MR/DD persons. However, not all beds in all institutions have qualified for ICF/MR certification, and those programs which have been certified may not always conform to all provisions of the ICF/MR standards. Eighty-seven percent of all public institutions with 16 or more beds are ICF/MR certified, and most States have certified all institution beds. 9/ Most of the non-certified beds are in 10 to 12 States. Beds in institutions can be certified even if they do not meet all ICF/MR standards if there is a plan of correction to bring the beds up to

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9/ From Feb. 9, 1984, telephone conversation with Charles Lakin, Ph.D., Center for Residential and Community Services, University of Minnesota. Data from 1982 National Census of Residential Facilities.

standards. The certification process is not supposed to allow repeat deficiencies, but most of the reported abuses have generally been known for some time. 10/

States have the responsibility to determine whether a facility is eligible for Medicaid certification and is meeting ICF/MR standards. If facilities are found out of compliance, Medicaid funds can be disallowed or deferred until the facility is brought into compliance. In addition to funding penalties, legal action can be initiated.

B. Litigation and State Actions

Numerous court cases have revealed the physical and psychological abuses which have taken place and continue to take place in some institutions for MR/DD persons. There are currently dozens of such court cases underway. For example, in Youngberg v. Romeo [457 U.S. 307 (1982)] the Supreme Court found that institutionalized mentally retarded persons have the right to adequate food, clothes, shelter and medical care, the right to personal safety, the right to freedom from unnecessary physical restraint, and the right to training necessary to further their interest in safety and freedom from undue restraint. 11/

Within the past three years, approximately 20 institutions have been scheduled to be closed.

10/ Ibid.

11/ Other major cases include Wyatt v. Stickney [344 F. Supp. (M. D. Ala. 1972), Affirmed in Part, Remanded in Part, and Reserved in Part, sub nom., Wyatt v. Aderhalt, 503 F. 2D] 1305 (5th Cir. 1974) and Pennhurst State School and Hospital v. Halderman [451 U.S. 1 (1981)] and [No. 81-2101 (Jan. 23, 1984)]

C. Civil Rights Statute

In 1980, the Civil Rights of Institutionalized Persons Act, P.L. 96-247, gave the Attorney General explicit authority to initiate and intervene in litigation involving the constitutional rights of institutionalized persons. The Attorney General is authorized to intervene if he believes that deprivation of rights is part of a pattern or practice of denial, if the suit is of general public importance, and if it is believed that institutionalized persons are being subjected to "egregious or flagrant" conditions which deprive such persons of any rights, privileges or immunities under the Constitution or laws of the United States. Since the enactment of this statute, the Attorney General has undertaken 41 investigations of institutions, 18 of which involved mental health or mental retardation facilities. 12/

12/ From testimony of William Bradford Reynolds, Civil Rights Division, Department of Justice before the Senate Subcommittee on the Handicapped, Nov. 17, 1983.

V. COMMUNITY-BASED SERVICES UNDER THE MEDICAID WAIVER

In an effort to increase home and community-based services to institutionalized aged and disabled persons, title XIX was amended in 1981 to allow the use of Medicaid funds for home and community-based services. 13/ The following groups may be served under the waiver program: the aged, the physically disabled, the mentally retarded, and the mentally ill. Section 1915(c) of the Social Security Act provides that Federal funds may be used to support home or community-based services (other than room and board) for persons who, but for the provision of such services, would require the level of care provided in Medicaid-supported institutions.

States must set forth a number of assurances to qualify for the waiver:

- o Safeguards are required to protect the health and safety of persons provided services and to assure fiscal accountability for the funds expended.
- o Persons entitled to institutional services are to be evaluated to determine the need for such services.
- o Persons determined to be likely to require institutionalization are to be informed of the alternative available under the waiver program.
- o The average per capita Medicaid expenditure for services under the waiver is not to exceed the average per capita Medicaid expenditure that the State would have made if the waiver had not been granted, i.e., the cost of community services is not to exceed the cost of institutional services.

13/ Title XIX was amended by P.L. 97-35 (Section 2176). This provision allows the Secretary of HHS to waiver certain requirements only available in institutions such as the availability of emergency care on the premises.

- o The States are to provide annual reports on the impact of the waiver program to include data on the type and amount of assistance provided and the health and welfare of the recipients.

As of July 1983, 28 waivers have been granted for programs serving MR/DD individuals. It is estimated that 15,600 MR/DD persons received community services under the waiver provision in FY 1983 at a total cost of $145 million. 14/

Regulations implementing the waiver provision include a cost formula which requires that a State's per capita Medicaid expenditures not increase with the waiver. 15/ An official of the Health Care Financing Administration (HCFA) stated that in considering Medicaid waiver requests, HCFA is considering both per capita costs and total ICF/MR costs. To meet these requirements a State must have fewer recipient days in institutions under the waiver than it would otherwise have had. States may do this either by transferring persons out of institutions into home or community settings or by placing in Medicaid-supported community facilities those preparing to enter institutions.

Services authorized under the waiver provision include case management services, homemaker/home health aide services and personal care services, adult day health, habilitation services, respite care and other services as approved by the Secretary.

A State may be granted a waiver for three years initially and the waiver may be extended for an additional three years unless noncompliance with the provisions of the waiver is determined during the initial three years.

14/ Information in this paragraph was provided by an official of the Health Care Financing Administration.

15/ 46 Fed. Reg. 48535. Oct. 1, 1981.

VI. COMMUNITY LIVING ARRANGEMENTS FOR MR/DD PERSONS

As MR/DD persons are transferred out of institutions and into community living facilities, many such persons are placed in foster care arrangements or in group homes in residential neighborhoods.

A 1982 study showed there were 63,703 MR/DD persons living in 13,862 community facilities of 15 beds or fewer. 16/ This represents a 35 percent increase in the number of such persons living in community facilities since 1977. Facilities serving six or fewer persons were primarily foster care arrangements. Facilities of 15 beds or fewer were predominantly privately operated.

The GAO recently completed a report which presents information on the issues encountered and the funding sources used in the establishment and operation of group homes for mentally disabled persons in seven States. 17/ The GAO report analyzes group homes for both the mentally retarded and the mentally ill, but the information summarized below relates exclusively to the mentally retarded where such distinction is possible.

Group homes are defined in the GAO report as community-based living facilities offering a family or home-like environment and supervision or training for 4 to 16 live-in disabled persons. The GAO found that a typical group home

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16/ From Feb. 9, 1984, phone conversation with Charles Lakin, Ph.D., Center for Residential and Community Services, University of Minnesota. Data from the 1982 National Census of Residential Facilities for Mentally Retarded People.

17/ Report by the U.S. General Accounting Office, An Analysis of Zoning and Other Problems Affecting the Establishment of Group Homes for the Mentally Disabled. Aug. 17, 1983, GAO/HRD-83-14.

accommodated six clients and was staffed by two persons. Group homes were generally found to be detached homes in residential neighborhoods with easy access to public transportation and community services. Some homes were in multi-family buildings or apartments. Local zoning ordinances often require specific permission before a group home for disabled persons may be established in a residential neighborhood. Group home sponsors usually have to assure that a facility will meet life-safety codes or the homes have to be licensed by local or State agencies. The GAO found that zoning and other land-use policies generally were not major hinderances in the establishment of group homes. According to the GAO, those sponsors who did encounter difficulty in meeting zoning and other land-use requirements faced burdensome or questionable requirements, waited longer and/or incurred extra costs before opening the group home. Zoning tended to hinder those sponsors attempting to open group homes in central city areas as opposed to other areas. The GAO found that 18 percent of the sponsors reported having great difficulty related to zoning, licensing, permit, or life-safety code requirements. (Life-safety codes caused the greatest difficulty.) About 15 percent of the sponsors closed, changed locations, or were unable to open a facility previously because of these requirements.

Funding was cited in the GAO survey as a greater problem than zoning or other land-use requirements in establishing and operating group homes. Thirty-eight percent of the group home sponsors reported experiencing a high degree of difficulty in obtaining funds to establish or operate their group home. Start-up costs, operational costs and lack of Federal funding were cited as the major funding problems. The GAO found that funding and sponsors for group homes for the mentally retarded were as follows:

Sponsors:

- o 65 percent had private non-profit sponsors.
- o 8 percent of the homes were proprietorships.
- o Most other group homes were sponsored by the public sector.

Start-up Funds:

- o 39 percent of the homes received private funds.
- o 55 percent of the homes received State funds.
- o 25 percent of the homes received local funds.
- o 13 percent of the homes received Federal funds, other than HUD Section 202 loans. Two percent used HUD Section 202 funds.
- o Charities and community fund drives also provided start-up funds.

Operating Funds:

- o 78 percent of the homes used clients' Supplemental Security Income (SSI) funds.
- o 65 percent of the homes received State funds.
- o 13 percent of the homes received ICF/MR funds.
- o Other operating funds included personal income, title XX (social services), local government funds, private funds, community fund drives and donations from charitable organizations.

According to the GAO, 26 percent of the group home sponsors experienced great difficulty locating suitable sites or facilities. These problems included finding accommodations with adequate bed and bath facilities, favorable landlord attitudes toward leasing, a safe neighborhood, and proximity to public transportation and medical and social services. The GAO found that 15 percent of the group home sponsors reported considerable difficulty in developing positive community relations, 13 percent had great difficulty obtaining community support and 12 percent had great difficulty educating the community.

Although most existing group homes received no community complaints, about 37 percent were the subject of complaints which mainly centered on perceived dangerous or unusual behavior of the clients, according to the GAO report.

VII. COST SUMMARY: FUNDS USED FOR RESIDENTIAL SERVICES FOR THE MR/DD POPULATION

A. Distribution of Public Funds

A report by the Office of the Inspector General of Health and Human Services estimated that for FY 1981, public spending for both residential and support services for the mentally retarded population was $11.7 billion. 18/ The Federal portion was estimated to be $5.4 billion and the State portion was estimated to be $6.3 billion. Approximately half ($5.9 billion) of the public funds were spent on residential care: $3.7 billion for care institutions; $0.7 billion for community residential facilities; and about $1.1 billion for care in other long-term facilities such as nursing homes and mental health institutions. This report estimates that at least $4.5 billion was spent on community-based support services which ranged from medical care to special education. It was estimated that about $1.3 billion in supplemental security income (SSI) and social security disability insurance (SSDI) payments were made to individuals living in the community; this $1.3 billion includes grants from States to counties which help pay for residential care and services. These data are summarized below:

18/ Placement Care of the Mentally Retarded: A Service Delivery Assessment, National Report to the Secretary, Office of the Inspector General, Department of Health and Human Services, Oct. 1981, p. 11.

TABLE 2. Public Funds for Mentally Retarded Persons: FY 1981
(in billions)

Fund Allocations		Amount Allocated
TOTAL FUNDING		$11.7
Source of funds		
1. Federal	(5.4)	
2. State	(6.3)	
Expenditures		
1. Residential care		$5.9
o Institutions	(3.7)	
o Community facilities	(0.7)	
o Other long-term care	(1.1)	
o Miscellaneous	(0.4)	
2. Community-based support services		$4.5
3. SSI/SSDI and State grants to counties		$1.3

During FY 1982, State and Federal payments for ICFs/MR totaled $3.6 billion; the Federal share was $1.98 billion. For FY 1983, ICF/MR payments are estimated to total $3.9 billion with a Federal share of $2.2 billion. Approximately 80 percent of ICF/MR funds are used in public facilities and 20 percent are used in private facilities. 19/

B. Per Diem Costs by Type of Facility

The cost of maintaining a MR/DD person varies according to the type of facility in which such person resides. The most expensive facility is the Medicaid-certified ICF/MR which is required to provide comprehensive services for very severely impaired MR/DD persons. The cost of a non-ICF/MR group home is

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19/ Data and estimates provided by an official of the Health Care Financing Administration. See Appendix D for ICF/MR funding since 1973.

apparently the least expensive. Community facilities were assumed to include support services. The results of the CBO cost estimate and the HHS Inspector General assessment are shown below. The CBO estimate projects cost for FY 1984 and the Inspector General report is based on FY 1981 data. The facilities in these two studies are not strictly comparable:

TABLE 3. CBO and Inspector General Per Diem Estimates for Persons with Mental Retardation

CBO Per Diem Estimates (FY 1984)		Inspector General Per Diem Estimates (FY 1981)	
ICF/MR (with 16 beds or more)	$104	ICF/MR (institution)	$80
Community-based arrangements (includes ICFs/MR of 15 beds or fewer and other community living arrangements)	78	ICF/MR (community)	65
		Non-ICF/MR group home a/	50
SNF	60		
ICF	50		

a/ Such group homes are financed with client SSI/SSDI payments, State funds, section 202 loans and section 8 rent supplements from the Department of Housing and Urban Development, food stamps, parent/resident fees, and voluntary sector contributions, according to the report of the Inspector General.

The ICF/MR regulations require a more intensive level of care and habilitation and training than is found in non-ICF/MR facilities. The Inspector General assessment found that the level of care required in an ICF/MR is inappropriate for certain institutionalized persons: those who could benefit from a more independent residential setting, those older persons who wish to "retire" from active treatment programs, and those so severely impaired that they primarily require services to prevent regression and health problems.

Employees of State institutions tend to be unionized and to receive more employee benefits than do persons operating community facilities. A recent cost study in one State found that institution staff are paid more and receive more fringe benefits than do staff in community programs, and that these differences account for much of the per diem differential. 20/ According to this Pennsylvania study, the average salary of an institution worker was $14,161 in FY 1982 compared to $9,304 earned by community residential program workers. Institution fringe benefits amounted to 36.4 percent of base salary whereas fringe benefits in community facilities were 21 percent of salaries. The specialization of labor in institutions and the medical focus of institution staff are major factors contributing to increased staff costs in institutions.

20/ Longitudinal Study of the Court-Ordered Deinstitutionalization of Pennhurst Residents: Comparative Analysis of the Costs of Residential and Day Services within Institutional and Community Settings, Dec. 15, 1983, Human Services Research Institute, Boston, Mass., p. 57.

VIII. SUMMARY OF S. 2053: COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983--OVERVIEW

On November 4, 1983, Senator Chafee introduced S. 2053, the Community and Family Living Amendments Act of 1983. The bill would shift Federal Medicaid funding for severely disabled persons from institutional care to community-based care in residential households and small facilities. The purpose of this proposal is to provide a strong incentive to States to move severely disabled individuals from large custodial institutions into small community-based facilities and to authorize services needed to maintain such persons in these small facilities. The institutions affected by this bill would be ICFs/MR, other ICFs, and SNFs. The bill would limit eligible community facilities to family-scale households (with certain exceptions). Under the bill, an institution would be allowed 10 years to reduce to zero the number of residents for whom ICF/MR reimbursement would be claimed. Certain small institutions (with 16 to 75 beds) would have 15 years. Facilities serving 15 persons or fewer at the time of enactment would not be required to reduce the resident population. A State plan would be required which would set forth the number of persons for whom the State would no longer claim ICF/MR payment for institutional services. After the transition period, Medicaid funds could only be used for institutional care if the care were not available in the community and if the period of institutionalization did not exceed 2 years.

S. 2053 would not require the transfer of MR/DD persons out of institutions, but after the transition period, States could not continue to claim ICF/MR payments for such persons as is currently authorized. Federal funding would be available for eligible community and family support services. States could opt to leave MR/DD persons in institutions at State expense, but Federal Medicaid reimbursements for such persons would be reduced to zero over the 10- or 15-year transition period, except for temporary institutionalization.

The bill is designed to alter funding and service patterns to severely disabled persons with substantial functional limitations whose disabilities were manifested before age 50. Disabilities due to advancing age are not included unless such conditions began before age 50. The bill would not include persons between the ages of 21 and 65 who suffer primarily from a mental disease. Mental disease is not defined, but the term may be assumed to include psychiatric disorders as opposed to mental retardation or physical impairments. The bill would require the identification of all institutionalized severely disabled persons and a community service plan would be required to be developed for each such person.

States would be required to enter into an implementation agreement with the Secretary of HHS which would assure a timely reduction of the institutionalized population claimed for ICF/MR payment and the development of services in community-based facilities. The agreement would assure the provision of services to further individual functioning and independence. Room and board would also be provided. If the provisions of the implementation agreement were not followed, States would be penalized by a reduction of Federal Medicaid funding. The bill would provide incentive Federal funding for services to persons transferred from institutions and living in community facilities for up to five years to encourage such transfers.

In introducing S. 2053, Senator Chafee stated:

> Under this Act, services to the disabled would be more individualized, providing for the special needs of each person. Those individuals needing 24-hour care, including medical attention would be provided this care in facilities within communities. Those needing

> fewer services, whether living at home, in foster care, in a group home, or in an apartment would also be provided with appropriate medical attention . . . .
>
> There will be those that will oppose this idea [the overall approach], at least at the outset. And I believe it is important for a very complete discussion to take place between those who support and oppose this concept of care.
>
> It is my hope that after debate, research, and discussion, my colleague will support this bill. I hope that process will improve it. But I am convinced that the need for an examination of the care provided to the severely disabled is desperately needed, and I strongly believe that this bill is an appropriate starting place. 21/

21/ From statement by Senator Chafee, Congressional Record, Nov. 4, 1983, p. S15485.

IX. DETAILED DESCRIPTION OF S. 2053

A. Reduction of Institutionalized Population

S. 2053, with certain exceptions, would require that Medicaid funding only be available to severely disabled individuals who reside in a "community or family living facility" (CFLF). A CFLF would be limited in size to three times the number of individuals in an average family household, or approximately nine beds. This restriction would not apply to facilities with 15 or fewer beds on the date of enactment if such facilities did not exceed 15 beds prior to enactment. Facilities or institutions with more than 15 beds could continue to receive Medicaid funding if they were in compliance with a written plan setting forth the manner in which the institution would reduce its population claimed for ICF/MR payment to zero within 10 years. Institutions with more than 15 and fewer than 75 beds would have 15 years to reduce such population to zero if the institution were built within 5 years prior to the effective date of the proposed Act. To remain eligible for Medicaid funding during this 10- or 15-year period, institutuions would be required to submit a report to the State every six months showing the number and identity of severely disabled individuals who had been transferred from ICF/MR payment status and the services planned for such persons.

In addition to the requirement that CFLFs not exceed three times the average family household size, CFLFs would assure provision of needed services and would be located in a residential neighborhood that could enable disabled individuals to participate in prevailing living, working and service patterns. A CFLF other than a natural, adoptive or foster home, would be required to meet safety and sanitation standards established under regulations by the Secretary in addition to those applicable under State law. Staff of CFLFs would be required to be trained or retrained in accordance with the State implementation agreement.

B. Eligible Use of Institutions

After the transition period, the bill would provide that Medicaid funds could be used for institutionalized persons only if the institution provided medical assistance that was necessary to the therapeutic objectives of the individual which was not available at a CFLF in the State, and only if the individual did not spend more than two years in the institution.

C. Eligible Persons

The term "severely disabled individual" would mean an individual with a disability that is attributable to a developmental and/or physical impairment, is manifested before age 50, is likely to continue indefinitely, results in substantial functional limitations in three or more major life activities (self-care, receptive and expressive language, learning, mobility, self direction, capacity for independent living, economic self-sufficiency) and reflects a need for services of an extended duration. This term would not include persons between the ages of 21 and 65 who suffer primarily from a mental disease.

A State would be allowed to use Medicaid funding for services to a severely disabled individual under age 18 (whose family was not eligible for Medicaid) if such person or his family spent at least 5 percent of adjusted gross income for the provision of care and services to such person.

D. Identification of Disabled Persons in Institutions

A community services plan would be required for every disabled individual residing in an institution that provides care supported by Medicaid funds. The plan would specify the types of assistance such person would require when transferred to a CFLF and would be formulated by an interdisciplinary team including community professionals, and as appropriate, the client, family or guardian.

E. Eligible Services in Community Facilities

Eligible services to be delivered in CFLFs include eligible care provided in institutions prior to enactment, home or community based services, independent living services, specialized vocational services, room and board and administrative services.

F. Accreditation of Community Facilities

Except for natural or adoptive homes, CFLFs are to be accredited by the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons or other national accrediting body, or licensed by an appropriate State agency.

G. Implementation Agreement

States would be required to enter an implementation agreement with the Secretary to ensure the following:

- o The proposed Act is to be implemented within specified time limits.
- o Services are to be continued for severely disabled persons who reside in institutions which lose Federal Medicaid support. (ICF/MR standards would continue to be enforce in such institutions.)

- CFLFs are not to be unduly concentrated in any residential area.
- Disabled individuals are to reside in a CFLF that is located as close to the natural, adoptive or foster home of such individual as is consistent with the best interests of such individual.
- Periodic, independent review of the quality of services in CFLFs is to be provided.
- Case management services are to be provided which include a written plan of assistance for each disabled person, review of the plan to determine the appropriateness of service and access to other social, medical or educational services.
- Fair and equitable arrangements are to be made to protect the interests of employees affected by the transfer of disabled individuals to CFLFs.
- A community service plan is to be developed for each disabled person residing in an institution. The plan is to be developed by an interdisciplinary team including professionals who deliver services in the local area and are knowledgeable about the person's disability.
- The parent or guardian of a disabled person is to be notified at least 60 days before such person is to be transferred to a CFLF. Provision are to be made for appeal of the types of services planned. The impending transfer could be appealed on evidence that the community services planned are not available in the neighborhood where the placement is to occur.
- CFLFs are to be accredited by an appropriate accrediting body or be licensed by the State.

The State plan making the assurances listed above is to include a copy of each written plan submitted by an institution to such State.

H. Funding Penalties for Noncompliance

Medicaid payments to States for administrative services would be reduced 5 percent in any quarter if during the prior quarter the Secretary found a State to be out of compliance with the proposed Act or with the ICF/MR requirements applicable to institutions. The State plan would be required to provide for periodic independent reviews of services to ensure that community facilities and institutions meet applicable standards. The independent reviewer would be required to submit a report to the Secretary at least every six months.

I. Funding Incentives for Transfers from Institutions

State would receive a 5 percent increase in the quarterly Medicaid payment for severely disabled individuals who resided in an institution prior to enactment of these amendments and resided in a CFLF thereafter. This incentives payment would apply to individuals living in CFLFs for less than 5 years.

J. Personnel Training

The implementation agreement would provide for training or retraining for persons who provide services in CFLFs.

K. Program Review

States would be required to provide for a review of care and services by an independent auditor for each fiscal year to ensure that the State was in compliance with the proposed Act. A report of the audit would be required to be submitted to the Governor, the State legislature, and the Secretary within 120 days of the close of the fiscal year. The Secretary could also provide for an independent audit. Audit findings out of compliance with the proposed Act could result in reduced funding. The Comptroller General of the U.S. would from time to time review State plans to ensure compliance with the proposed Act.

L. Complaints

Any interested party would be able to bring an action regarding an alleged violation of the proposed Act by a State plan. Such person could recover attorneys' fees should the party prevail. Not less than 30 days before starting the action the interested party would inform the Secretary of HHS, the U.S. Attorney General, and the State in which such action is brought.

X. DISCUSSION OF S. 2053 AND RELATED ISSUES

The introduction of S. 2053 has intensified debate regarding the appropriateness of institutional care, family-scale living and other levels of service and care for the MR/DD population. While all persons interested in care to this population favor quality residential services for MR/DD persons, there is considerable disparity regarding the types of care considered most appropriate. Some professionals, parents of disabled persons, and other advocates feel that a continuum of residential alternatives, including institutional care, should be available which are cost-effective and meet the various needs of MR/DD persons. Advocates of S. 2053, who also include professionals, parents of disabled persons, and other interested and informed persons, feel that family-scale living arrangements provide a superior service setting for all the needs of MR/DD persons by providing personalized care in a more normal, cost-effective setting.

A. Examples of Public Testimony

The following two statements taken from the public testimony are intended to illustrate the issues and the depth of concern felt by those persons who have taken positions for and against S. 2053. The first statement illustrate abuses found in some institutions. The second statement, specifically opposing S. 2053, expresses the concern that good institutional services should be maintained and that a choice of service settings should be available.

1. Examples of Institutional Abuse [22]

> Four beautiful little girls, unable to move to protect themselves, sleep in cribs where above their heads the ceiling is visibly crumbling. From the superintendent, "I'm afraid with the next big rain, this ceiling is going to collapse." Jane, confined to a bed, in a building without working air conditioning where summer temperatures are commonly in the upper 90's and low 100's. Jane and all of her companions, who are infested with flies spring, summer and fall because they cannot move their arms to swipe them away and because there are no screens or screens are ripped and torn. Johnnie, who for most of his waking hours does not have furniture to sit in, and must fight with 20 other people to sit in a hard plastic chair. Joe, who spends his days in the living area, a large room, banging his head against the wall or biting his hands. Why? There is no other stimulation for him, no games, no toys, no recreation equipment. James, in 30 degree temperatures walks to his program building in sneakers without any socks as well as no coat. June, who doesn't go to her program because there aren't any clothes. Geremi, sent home to his parents in a pair of shoes with nails protruding through the soles into his feet. Jonathan, who walks around spending the day pulling up his pants because they fall off. Pattie, who bites other people and chews on her fingers. She bites because she is hungry, she is hungry because although she is supposed to be receiving double portions of food at meal time, the kitchen doesn't have enough food to provide her with double portions.
>
> Lisa, a beautiful little girl, frail and thin, becoming chronically undernourished. Why? She doesn't receive prescribed dietary supplements and she is fed so rapidly, most of the food which goes in her mouth ends up coming back out. Kitchens, which change nutritionally balanced meal plans because there is an inadequate supply of foods. Mary Ann, who has waited almost two hours to be fed while her tray has been sitting in the open to be infested by flies.

This witness testified that there are inherent disincentives for change within institutions. According to this testimony: some States take funds from good institutions to help upgrade poor ones; supervision and evaluation of institutional services is sometimes done by State or contracted employees "reluctant to bite the hand that feeds him;" some States are under pressure to maintain institutionalized populations to recover from the Federal Government part of the cost of capital expenditures in such institutions.

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[22] Taken from testimony of Kathy A. Schwaninger, Executive Director, Working Organization for Retarded Children, Queens, New York. Presented to Senate Subcommittee on the Handicapped, Nov. 17, 1983.

2. Need for Continuum of Services 23/

> The true thrust of this legislation [S. 2053] is that size equals quality. The agency that serves developmentally disabled children and adults in ten 10-bed facilities is inherently providing higher quality, more individualized services to its residents than is the agency which operates a 100-bed facility. Never mind the fact that the "institution" has better staff ratios, more qualified staff, heavy family involvement, on site health services, and is overseen by a voluntary, community board of directors. Never mind the fact that the organization has been providing caring, quality services for the developmentally disabled for the past 10-20 years. Never mind the fact that the residents have developed healthy, long-standing relationships in a supportive atmosphere. And never mind the fact that the family is finally comfortable that after looking for years, being on waiting lists for years, that this facility is appropriate for their son or daughter. No, never mind all these minor factors. It's no good--it's too big . . . . We must acknowledge that there is a strong and definitive difference of opinion regarding what constitutes the correct "quality of life" for the mentally retarded. I am adamantly in favor of leaving as many choices and options open as is possible. I am strongly in favor of expansion of many types of residential services for the retarded, including small group homes. I am supportive of any changes in the current system which would ensure that regulations be applied uniformly. I am in favor of the strict enforcement of any regulations which enhance the quality of life for the retarded in all facilities, large or small.

B. Overview of Research Findings

Although emperical research on the subject is not conclusive, most studies tend to support the contention that community-based services conducted in as normal a setting as possible are more effective than institutional services in promoting developmental growth and independence of MR/DD persons. A move from institutional to community settings tends to result in positive social adjustment and improved behavioral development for many MR/DD persons. However, for developmental growth to take place, according to research findings, the community setting must include certain essential features: effective teaching

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23/ Taken from testimony of Peter Mule, Executive Director, Riverside Foundation (a not-for-profit ICF/MR), Lincolnshire, Illinois. Presented to the Human Service Committee, Evanston City Council.

technologies, friendship networks for MR/DD persons and active involvement and positive attitude of care providers. Some research has found that large institutions in which these features are present are also effective settings for development growth and that reducing the size of a facility does not necessarily change the daily pattern of care.

Research indicates that there is great variation in community care facilities. They range from small family care units to larger segregated replicas of institutions. To provide as normal an environment as possible, community facilities need to be enriched with positive programming within the facility and meaningful contact and exchange with activities and services outside the facility. That is, the community facility must be therapeutic as opposed to being merely custodial. Studies have shown that clients in community care facilities benefit from increased interaction with qualified care providers within the community facility and from involvement in community activities and services outside the facility. The more educated care providers tend to promote increased client interaction and increased contact with outside activities. 24/

S. 2053 represents an effort to optimize the benefits of small, family-scale and community living arrangements for virtually all of the institutionalized MR/DD population. By specifying the services which must be provided in the community facilities, the bill attempts to ensure that the clients get necessary health care and developmental training in as normal a setting as is possible. Advocates of S. 2053 have argued that proper education, training, community intergration and social interaction are simply not possible in isolated institutions with their history of abuse.

24/ See Appendix D for selected bibliography which includes research on which this section is based.

On the other hand, those who oppose S. 2053, or wish to see the bill modified, argue that while family-scale living arrangements may be appropriate for most of the institutionalized MR/DD population, facilities of over nine beds may be more economical and may be an equally effective setting for training for some of the MR/DD population. It is argued by some that there is opportunity for socialization in larger facilities where training and recreational activities help create social relationships within the institutionalized MR/DD group.

C. Federal vs. State Decisionmaking

Under current law, States make the decisions regarding whether an individual's care is provided in an institution or in a community setting. S. 2053 would, in effect, make the decision at the Federal level because after the transition period, ICF/MR funds would generally only be available in community settings. States have developed various approaches to the care of MR/DD persons that include institutional and community care settings. S. 2053 would require that all States conform to the same Federal requirements regarding service setting to qualify for Medicaid funding.

States might argue that this decision is an appropriate State function and that considerable capital outlays have already been expended to bring institutions up to ICF/MR standards. Much of this expenditure was financed through bond issues that are predicated upon the receipt of Medicaid payments in future years. In response to this concern it might be argued that States could use the institutions for nursing homes, juvenile justice facilities or other residential purpose.

D. Expanded Caseload

Many MR/DD persons are maintained at home by families who are reluctant to institutionalize them. Other MR/DD persons reside in non-medical home care facilities and in board and care homes. By making community facilities and services available, additional demands may be created on behalf of MR/DD persons not currently served in Medicaid-funded facilities. This phenomenon could increase total Medicaid expenditures.

There are various informal estimates regarding the number of MR/DD persons who may be eligible for Medicaid-funded services under S. 2053. Estimates of eligible persons range from 625,000 to 2 million more than the 138,738 persons who received ICF/MR services in 1982. 25/ It is not known how many of the eligible persons would come forth and request services under S. 2053, but case management, independent living services and respite care are services needed by most, if not all, non-institutionalized MR/DD persons and their families. Since S. 2053 would not put a cap on the amount of Federal funds authorized under S. 2053, program eligibility directly effects possible costs.

On the other hand, community services have been shown to be considerably less expensive than institutional services, especially for persons living with their families, so it may be possible that the same amount of Medicaid funding would serve considerably more persons in the community than in institutions.

25/ Estimates range from approximately 625,000 (by an official of the National Association of State Mental Retardation Program Directors), to 1.2 million (by an official of the Association for Retarded Citizens) to 2 million (by Charles Lakin, Center for Residential and Community Services, University of Minnesota).

E. Medically Fragile Clients and Clients with Severe Behavior Disorders

One issue frequently raised is the concern that medically fragile MR/DD persons who require 24-hour nursing care and frequent physician services may be served more efficiently in institutions where emergency services are available at all times. It is estimated that 25 to 30 percent of the institutionalized MR/DD population is either medically fragile or has very severe behavior problems, and it is argued by some that these persons may be more appropriately served in facilities of more than nine persons.

Advocates for S. 2053 argue that these medically fragile clients and clients with severe behavior disorders can be appropriately served in family-scale facilities more humanely and with lower costs.

F. Reactions of Some Parents of Institutionalized Persons

Some parents of institutionalized MR/DD persons are strongly opposed to S. 2053 because they feel that their family member is getting appropriate, effective care in an institution; the parent want the security that they feel they have in the institutional setting; and they do not want the Federal Government to legislate against their choice of care for their MR/DD family member. Such parents want the assurance that their offspring will continue to receive care after the parents die. Some such parents fear that community services may become fragmented, may be discontinued, and may not provide the total care provided in one setting by an institution. Some parents are also concerned that S. 2053 does not offer the chance to resume institutional care if the community placement does not work out.

On the other hand, there are some families of institutionalized persons who would prefer to have their MR/DD family member in a more normal therapeutic community setting nearer to the rest of family and would support S. 2053 because it would make more funds available for this purpose. There have been experiences in which families who were initially opposed to deinstitutionalization changed their opinion as they saw positive results following the transfer of institutionalized persons to community facilities. 26/

G. Expanded Use of the Medicaid Waiver Provision

Rather than transfer funds out of institutions according to a specified timetable, as is proposed under S. 2053, it has been argued that community services for MR/DD persons can be expanded by the States through wider use of the Medicaid waiver provision. Another alternative could be to authorize Medicaid funding in community facilities as an option under Medicaid, rather than using the waiver provision. It is argued that these approaches would allow the spectrum of services to be expanded rather than diminished. An expanded Medicaid waiver or community care option could maintain Federal funding in both institution and community settings.

On the other hand, it is argued by advocates of S. 2053 that it would be prohibitively expensive to try to maintain a dual system of institutional and community services and that community services are cheaper. (However, during the 10- or 15-year transition from institution to community services, there would be a dual system as MR/DD persons were gradually moved out of institutions. Advocates for the bill argue that considerable leverage is necessary to change the major focus of services for the MR/DD population from institutions to small community service settings.

26/ For a discussion of court cases involving the wishes of parents, see Deinstitutionalization, Zoning and Community Placement, Mental Disability Law Reporter, vol. 7, no. 5, Sept.-Oct. 1983. p. 375.

H. Community Readiness

It has been argued that many communities are not ready to receive MR/DD persons in large numbers from institutions. It is clear that nearly all institutionalized MR/DD persons require care and or supervision. Communities would need to develop facilities for some MR/DD persons which would be barrier-free and which would meet life-safety codes required for MR/DD persons not able to respond appropriately to life-threatening dangers. The capital outlay for such facilities could represent a considerable expense not addressed in S. 2053.

It is the purpose of S. 2053 to provide a strong incentive to States to develop and expand community and family support services. The 10- to 15-year time frame provided in the bill is intended to allow time for the development of community and family services. The major effect of the bill, moving Federal funds from institutions to family-scale facilities, would provide some of the resources necessary to develop community facilities. Advocates of S. 2053 argue that as long as nearly all Federal funding is used in institutions, communities will not have the resources to expand services.

I. Reactions of Facility Operators and Unions

Owners and operators of proprietary institutions, who may have invested considerable funding to bring the facility up to ICF/MR standards, may fear a loss of profits or may go out of business if S. 2053 were enacted. On the other hand, under S. 2053 these persons could possibly sell the institution and apply for Medicaid funds to develop the types of facilities eligible under the bill.

Governors may oppose S. 2053 because it would require the loss of Medicaid funds to continue support to institutions. States interested in developing family-scale facilities, however, could obtain increased assistance under the proposed approach.

Some State institution employee unions may oppose S. 2053 because it is felt that institutional services are more appropriate for some MR/DD persons. It is argued by some advocates of the bill that this opposition is based on fear of losing jobs. It might be argued that State employees currently working in institutions could become care providers in community facilities.

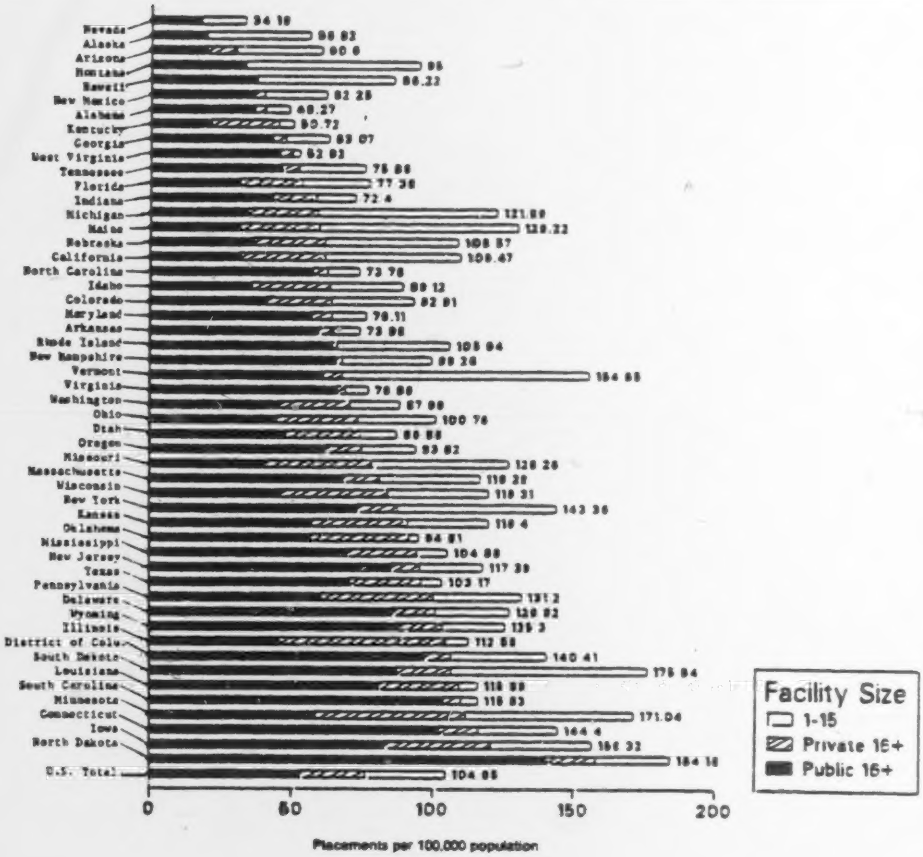
APPENDIX A: TERMS USED TO DESIGNATE THE CLIENT POPULATION

Various terms are used to refer to the severely disabled, primarily mentally retarded population which may receive services in these institutions. The Medicaid program, authorized under title XIX of the Social Security Act, provides Federal funds to help support services for "mentally retarded or persons with related conditions" who require institutional care. S. 2053, which is in the focus of this paper, provides definition for "severely disabled individual" which is based on the definition of "developmental disability" under the Development Disabilities Assistance and Bill of Rights Act, P.L. 91-517, as amended. (The definition included in S. 2053 is presented on page 26 of this paper.) A memorandum from the Congressional Budget Office (CBO), which provides a cost analysis of S. 2053, refers to "MR persons."

This paper uses the term "mentally retarded and other developmentally disabled" (MR/DD) persons, a term commonly used in the field, to generally encompass the population referred to in the above documents. Because S. 2053 would affect Federal funding used for severely disabled individuals, the term MR/DD as used in this paper refers to severely disabled MR/DD persons in need of lifelong or extended services, and not to those mildly impaired persons able to function relatively independently.

The term "severely disabled individual" as defined in S. 2053 includes certain severely physically impaired, mentally alert persons who meet the functional definition in the bill. The data presented in this paper do not include this population because they have traditionally not been considered part of the MR/DD population, are generally not served in ICFs/MR and are not included in the major studies of institutionalized disabled persons.

APPENDIX B: MENTALLY RETARDED PEOPLE IN RESIDENTIAL CARE PER 100,000 STATE POPULATION BY SIZE OF FACILITY: UNITED STATES, 1982 (100% REPORTING)

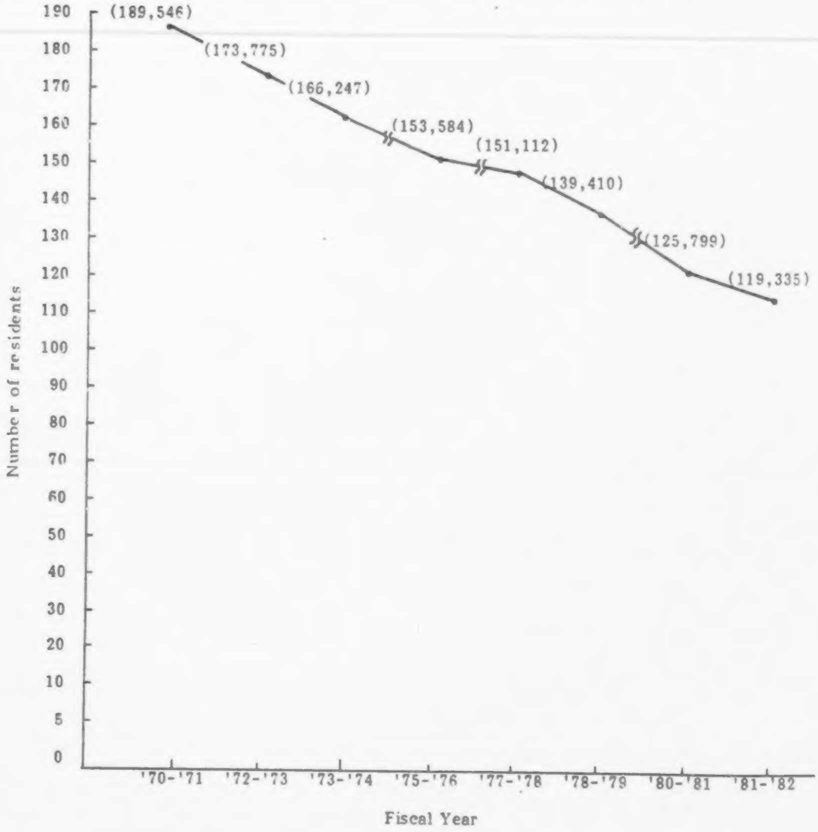


Appendix B presents the number of mentally retarded people per 100,000 of the population living in smaller facilities (1-15 residents) and in larger public and private facilities (16+ residents). States are rank ordered according to the per capita rate of placement in large facilities.

- o Approximately 105 of every 100,000 people in the U.S. were placed in residential care for the mentally retarded, with 76 of these individuals place in larger facilities.
- o State placement rates in larger publicly operated facilities ranged from 18 to 140 per 100,000 people. Most states (38) placed more people in large public facilities than in either larger private or smaller facilities.

Source: Brief #21, 1982 National Census of Residential Facilities: Summary Report, Center for Residential and Community Facilities, fall, 1983.

APPENDIX C: AVERAGE DAILY POPULATION OF MENTALLY RETARDED PERSONS IN PUBLIC RESIDENTIAL FACILITIES: FY 1970--FY 1982



Source: Public Residential Facilities for the Mentally Retarded. 1982. Published by National Association of Superintendents of Public Residential Facilities for the Mentally Retarded. p. 4.

APPENDIX D: TOTAL AND FEDERAL ICF/MR EXPENDITURES AND NUMBER OF PERSONS SERVED

Fiscal Year	Expenditures Total	 Federal	Persons Served
	(in millions)	(in millions)	(in thousands)
1973	$ 165	$ 98	29
1974	203	120	39
1975	349	204	54
1976	602	349	83
1977	871	501	101
1978	1,162	662	98
1979	1,493	844	115
1980	1,977	1,107	125
1981	2,927	1,624	196
1982	3,609	1,985	154
1983 (est.)	3,911	2,151	132 a/

a/ The estimate of persons served in FY 1983 was provided by Wayne Smith, Health Care Financing Administration.

Source: Data were provided by Ian Hill, Budget Analyst, Program Benefits Branch, Division of Budget, Office of Financial Management Services, Office of Management and Budget, Health Care Financing Administration.

In addition, under the Medicaid waiver during FY 1983, 15,600 persons were served at a total cost of $145 million, according to estimates of the Health Care Financing Administration.

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Senator DURENBERGER. The hearing will come to order.

Recently much of the attention of this subcommittee has focused on medicare. We have had a full agenda, closely monitoring the legislative proposals regarding the prospective changes.

This year, however, we will begin to expand our focus to health care services for the economically disadvantaged. Over the course of at least 10 hearings in 1984 we will examine how our goal of equal access to quality care in America will be reached. To do that, we will begin to look at who is economically disadvantaged, what services are now provided, how these services are provided and financed, and what changes need to be made.

An important part of our examination will focus on how much society is willing to pay to provide quality care to all Americans.

Our hearing today will cover an important area of medicaid reimbursement long-term care services. Specifically, we will focus on the Community and Family Living Amendments Act, sponsored by our colleague Senator John Chafee.

This legislative proposal would seek to provide more individualized services for the severely disabled by shifting Federal medicaid funds from institutions for the disabled to the community-based setting. Those most directly affected by this proposal are mentally retarded and developmentally disabled individuals.

While the quality of services that the Government reimburses is of utmost importance to us, we cannot ignore the question of cost. We are now spending more than 10 percent of our gross national product on our acute health care system, our sick care system. The more these costs rise, the less available are resources for health care, preventive health care, and a variety of other services that address the ongoing needs of all Americans including the chronically disabled

Reality requires that we establish policy within a framework of resources, and that means a policy which results in cost-effective and cost-efficient health care as well as compassionate health care delivery.

Primarily because of the last decade's rapid growth of payments for care and intermediate care facilities for the mentally retarded, medicaid has become a principal source of Federal financial assistance for the mentally retarded and other developmentally disabled persons.

Medicaid expenditures for ICF/MR's have become the program's fastest growing category, rising from less than $200 million in 1973 to almost $4 billion in 1983. These increases have been drastic, even when viewed against the rapid growth in overall nursing home expenditures.

The expenditures for ICF/MR's have increased at an average annual rate of approximately 34 percent each year from 1976 to 1981, more than double the 15-percent increase for all other long-term care services, and almost triple the annual growth rate for all medicaid expenditures.

Medicaid reimbursement is paid to formal providers of care, which leads to its so-called institutional bias. Facilities providing institutional care for mentally-retarded persons currently range in size from 16 to 2,000 beds, although most ICF/MR facilities are over 200 beds.

Today we will examine a proposal that would modify medicaid reimbursement so as to redirect it to small community-based providers of care. We realize the strong sentiments that are held on the issue of the institutionalization.

This hearing provides members of the committee with an opportunity to hear from a broad range of people with differing views on the issue. The presentations of these views will help us as we consider this most important legislative proposal.

I look forward to hearing from our witnesses today, witnesses that represent organizations, institutional providers, community providers, parents, and recipients of care. I hope you, all of you, will help us think through how we can insure that the Government pays the best price for the highest quality of appropriate care, and I thank all of you, and I thank each of you, for coming this afternoon and taking the time to explore the proposal that is before us.

I will turn at this time to my colleague Senator Chafee.

Senator **Chafee**. Thank you very much, Mr. Chairman.

Mr. Chairman, I would join you in thanking all of those who have come here today to participate in these hearings. Most notably, I thank Chris Craddy, who lived for many years in a large institution in my own home State of Rhode Island and is now living in a community-based home. Chris will share with us her personal feelings about life in this different setting.

We will also hear, as you noted, Mr. Chairman, from experts who are involved in the care of the severely disabled and retarded both in large institutions and community-based homes.

Also, we will hear from several parents of retarded or disabled individuals.

Now, some time ago I read something I would like to share with you today. It was entitled "The Seven Steps to Stagnation": (1) We've never done it that way; (2) we're not ready for that yet; (3) we're doing all right without it; (4) we've tried it once, and it didn't work out; (5) it costs too much; (6) that's not our responsibility; (7) it won't work.

This bill gives us the opportunity to take some positive actions on behalf of those who most need our help These hearings provide us with a long overdue forum in which we can closely scrutinize the current system of care and determine how it can be improved to benefit those who need it most.

Now, this legislation is highly controversial. One has only to take a look out in the hall as well as in this full room and another full room upstairs to realize that it evokes tremendous emotion.

It is crucial, it seems to me, as we discuss matters this afternoon, to realize that we all share a common purpose; we are all trying to work toward one goal, and that is to provide the best possible care to our retarded and disabled citizens who are not able to care for themselves.

Our goal today is to determine how this purpose can best be accomplished, at the same time working within the financial constraints that were mentioned earlier.

Since I introduced this bill last November I have received questions about the stability of group homes, the advisability of the 10 to 15 year shift of Federal funds to community programs from larger facilities; the eligibility requirements of the patients; the cost; and finally, the question that comes most often, how the States will be able to develop viable community-based facilities that provide high quality care.

I hope that we can address all of these questions this afternoon to the satisfaction of everyone who has expressed such heartfelt interest and concern.

Now, Mr. Chairman, it is no secret that all of us fear the unknown. That's why we are here today, to examine this idea of group homes, which is new and different and unknown to most of us. We are here to learn from those who will testify—to learn from their knowledge and their experience.

We should not deny our retarded and disabled citizens the opportunity to grow and to participate in the community, because of our own ability to grapple with the unknown. The Congress and our Nation have always strived to better the current situation; we have never been satisfied with the way things are. We want to move ahead as a Nation. We have done that with a host of different proposals that have come before us, not just in the health sphere but in all kinds of activities.

And so, as we have tried to strive to improve the situation in the past, how can we ask any less than to strive to improve the current situation for the patients of our institutions?

Thank you.

Senator DURENBERGER. Thank you.

Senator Pell.

STATEMENT OF HON. CLAIBORNE PELL, U.S. SENATOR FROM THE STATE OF RHODE ISLAND

Senator PELL. Thank you very much, Mr. Chairman, for letting me be here.

I just wanted to strongly endorse and support the efforts of my colleague Senator Chafee in this bill. I have been very impressed in our own State of Rhode Island to see that since I first came to the Senate in 1960 when we had a population of 1,300 in our home for the retarded, that is now less than 400. And this has accompanied savings to the State and accompanied a better style of life and a better quality of life for the people who are institutionalized.

I would hope that this hearing will shed more light on this difficult subject, and I am glad to be here in support of the idea that the fewer people in big institutions, the more in smaller and more affectionate, if you want to use that word, and more close-reaching surroundings, the better off we are.

Senator DURENBERGER. Thank you.

I know Jim Exon has had a little experience with this area that goes back to being Governor of Nebraska, and we welcome his being here today.

Jim, we look forward to your comments.

STATEMENT OF HON. J. JAMES EXON, U.S. SENATOR FROM THE STATE OF NEBRASKA

Senator EXON. Mr. Chairman and members of the Subcommittee on Health, I would like to take just a few moments, if I might, to present a written statement from a constituent of mine about S.

2053, and comment that as a former Governor and before that as a private citizen I have been actively involved in support of and improvement in all programs for mentally retarded citizens. We Nebraskans are proud, proud indeed, of our accomplishments and leadership in this important area.

The statement is from Ms. Patricia Crawford, who is the Government Affairs Chair of the Nebraska chapter of the Mentally Retarded Association of America.

The State of Nebraska has been a party to an expensive and lengthy court battle with which I was involved during my years as Governor. Many of the issues raised in S. 2053 were encompassed in that lawsuit. Ms. Crawford has been involved in mental retardation issues for a number of years and offers some firsthand testimony about the issues and problems raised by this proposal.

The major concern of Ms. Crawford and my own concern about this bill is that it will deny the freedom of choice to parents and families of the mentally retarded and the disabled.

Mr. Chairman, the lawsuit that I referred to resulted in a number of changes in our State's large facility, which has been improved, in the quality of care that has been provided there.

The real issue, it seems to me, should not be the size of the facility where the mentally retarded and the disabled are served, but rather the quality of care that they receive.

Some witnesses will likely to tell you today that bigger is not necessarily better for the retarded and the disabled. I submit that the reverse is also true, that smaller is not necessarily always better.

Some mentally retarded and disabled persons would undoubtedly be best served in smaller community-based facilities, of which we have a great number in Nebraska; but not all disabled and retarded people are alike. And some may be best served in a larger facility.

The bottom line is that parents and families of the mentally retarded and disabled should have as many alternatives as possible and should be able to choose for themselves what type of facilities they desire for the treatment of their loved ones.

Mr. Chairman, the statement of Ms. Crawford outlines a number of concerns about the bill being considered and relates Nebraska's experience in this area.

I would respectfully request that her statement be received and be made a part of the permanent record of this hearing, and I urge that we proceed on the basis of caution in this complicated area.

Thank you very much, Mr. Chairman.

Senator **DURENBERGER**. Thank you for your statement, Senator, and without objection Ms. Crawford's statement will be made part of the record.

[The prepared statements of Senator Exon and Ms. Crawford follow:]

PREPARED STATEMENT OF SENATOR EXON

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I submit that the reverse is also true—that smaller is not necessarily always better. Some mentally retarded and disabled persons would undoubtedly be best served by living in smaller, community-based facilities. But not all disabled and retarded people are alike, and some may be best served in a larger facility. The bottom line is—the parents and families of the mentally retarded and disabled should have as many alternatives as possible and should be able to choose for themselves what type of facility they desire.

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STATEMENT OF PATRICIA KELLY CRAWFORD

1307 Crestdale Rd.
Lincoln, Nebraska 68510

Presented on behalf of the
Mental Retardation Association of America, Nebraska Chapter
before the Senate Finance Committee
Subcommittee on Health
February 27, 1984

Regarding S. 2053, The Community and Family Living Amendments
Act of 1983

Has anyone ever come to your church on a bed?

It is a regular occurrence at the Beatrice State Developmental Center, Beatrice, Nebraska, the only Nebraska public institution dedicated to the care of the mentally retarded. Because it is a community built especially for the multiply handicapped, many ordinary hazards have been eliminated from the design. For instance, there is no deep end in the swimming pool. The 10 ultramodern cottages are barrier-free for those residents in wheelchairs or who are on mobile carts because of inability to sit up. The streets have a 15 mile per hour speed limit. Even the bathtubs are special; several are deep and cylindrical and have a hydraulic chair to lower the bather into the swirling warm water for several minutes--it must feel great to someone who has spent the day in a wheelchair.

Broad green lawns, air-conditioned housing, special trailers to transport the folks on mobile carts, dances, birthday parties, Scouts and camping are features of the Beatrice campus, plus a host of experts to train, teach, program, nurse and doctor the residents of this unique community. The Center is accredited by the Joint Commission on Accreditation of Hospitals.

A joint effort by the taxpayers of Nebraska plus the federal Medicaid program has provided the opportunity for the most severely handicapped Nebraskans to enjoy the "good life."

How much will it cost for the taxpayers to throw away and replace this community, to break it up and scatter it about, just because of an idea--that many experts simply do not buy. And I can promise you, the parents of these severely and profoundly retarded adults don't buy it either!

Eighty percent of the population of public residential facilities for the mentally retarded is comprised of the severely and profoundly retarded; 43.1% of the residents have other handicapping conditions in addition to mental retardation. The most common are blindness, deafness, epilepsy and cerebral palsy. The most common of all is mental illness, occurring in 36% of the residents (R.D. Scheerenberger, Ph.D., Public Residential Facilities for the Mentally Retarded, 1982). All but a few mildly or moderately retarded people residing in institutions have other types of problems, such as blindness, deafness, cerebral palsy and epilepsy or behavior problems. Do not ignore this fact.

Profoundly retarded individuals generally cannot aspire to a mental age more than 2 to 2½ years and even in adulthood will rarely have any intelligible speech. Total life support is essential to their survival and up to 40% are either bedfast or semi-ambulatory. The average age of death is below 40. (Beatrice Daily Sun, Beatrice, Nebraska, September 27, 1980)

Mental Retardation Association of America, Nebraska Chapter, is eight years old; 99% of our members are parents and relatives of retarded adults. Two-thirds of our retarded loved ones live in congregate residential centers; one-third are in community programs. Because of the wide ranges of abilities and disabilities in the retarded population, with IQ's which range from 0-70 points, our members support a continuum of services. A full range of services includes residential centers for the most severely handicapped, well supervised community based group homes, supervised living, and independent living for the most able. As parents and/or legal guardians, we should be able to choose the most beneficial program for our children.

Years ago many of our members banded together to start community programs. Over time, some of these same people came to realize that the very programs they started did not meet the needs of their retarded children. All retarded people are not alike! Some of our members were instrumental in starting their local Association for Retarded Children, and almost all were formerly members of that organization. Once the Association for Retarded Children adopted the goal of closing all institutions for the mentally retarded, organizations like the Mental Retardation Association of America, Nebraska Chapter, began to spring up all across the country--like mushrooms after a rain--to advocate a full range of services to meet a full range of needs.

Robert Isaacson, Ph.D., in his book, Meeting the Needs of the Retarded, says, "The aim of programs for the mentally handicapped should be to provide those conditions and circumstances that are most conducive to their happiness and personal growth. Programs of education and vocational training should be supportive of these goals, rather than ends in themselves."

This is a new approach for many, in a work-oriented society, but certainly it is a more common sense approach for those who are profoundly or severely retarded.

Most people have never seen a severely retarded person, which is one of the reasons it is so difficult for the public to understand how their needs differ from those of the mildly retarded in such goals as employment and independent living, and why a good institution is usually their best environment.

We are talking not just about persons who can't talk or read, but persons who have multi-handicaps. Many of these persons may never see, walk, or be able to push their own wheelchair, never be able to hold a spoon, or comb their hair, or brush their teeth. They will learn the simplest of skills only after years of effort. Many are completely unaware of their surroundings. Staff, trained in motivation techniques and the value of praise and the soft, loving touch, can go no futher than the deficient brain will allow.

Following are personal stories of young adults who need good institutional care, now made possible at Beatrice State Developmental Center and private institutions in Nebraska, through the aid of Medicaid funds that would be threatened by S. 2053. If Medicaid funds are phased out, the fine Nebraska institutions will drastically decline in quality or close altogether. Medicaid pays 57% of total costs.

JANICE ADAM

Janice, 35 years old, is profoundly retarded, epileptic, and blind, and has had severe emotional problems.

At ages 4 and 5, Janice attended the Child Developmental Laboratory, a child care center at the University of Nebraska (a part of their child training program).

This was followed by attending the School for the Blind, then private tutors at home. Her learning development was negligible and she was showing emotional problems.

Janice then spent several months at the Boston Center for Emotionally Disturbed Blind Children, testing at the famous Menninger Clinic, and the Nebraska Psychiatric Institute. All three advised placing Janice in an institution for retarded persons.

Janice entered the Beatrice State Developmental Center at the age of 13 and remains there at 35. She lives in a cottage, sharing a room with one person. Janice's speech and learning ability is very limited, but she has two interests, swimming and music. She has her own piano (plays by ear) and swims in the Center's indoor pool.

Janice's mother, now a widow, visits her weekly. She is comfortable about Janice's individualized programming and care and feels the advice to place Janice in a structured living environment was wise. Janice's behavior problems have modified and she is able to go (escorted, because of her blindness) to activities in the Center's auditorium, park, chapel and restaurant. The Beatrice State Developmental Center is truly Janice's home and community.

DAVID SHAPLAND

David, now 34, was a normal child until, at 17 months, he had meningitis and was left mentally retarded with seizures.

At the age of 7 he was committed to the Beatrice State Developmental Center, with an average of 20 seizures a day, and he had to be diapered at all times.

After 22 years at Beatrice State Developmental Center, his seizures were under control. He had been trained in janitorial services and had also worked in the laundry and some sheltered workshop programs. . He had no disciplinary problems and got along well with staff.

The court-ordered de-institutionalization program moved David into a community program, where he lived in a basement with no fire exit.

In the community program many problems arose. Four years later his seizures were no longer controllable, and his final evaluation papers reported he was a constant problem, hard to manage and uncooperative.

David was then admitted to a church-sponsored residential institution. At the end of the first year he no longer has seizures nor behavioral problems, is happy, and is working in a rug-making program.

Without the Medicaid program, David, at best, would be an unhappy man in a community program; at the worst, he might be vegetating at home, feel unproductive and completely frustrated.

The great fear, expressed by his parents (now retirement age), is that Medicaid funds might be cut off by passing S. 2053 and that David might some day become a street person. There is no other family member to assume his care.

KATHY NORTON

Kathy began school in a special program in Kent, Washington. After her parents moved to Nebraska, Kathy was admitted to the Beatrice State Developmental Center at the age of eight. She was diagnosed as retarded with behavior problems.

Kathy was making good progress throughout her 10 years at the institution. However, when she was 18, her parents, bowing to the de-institutionalization movement and the court decree, consented to having her enter a community program.

In the community program she regressed, becoming a severe behavior problem. She was disciplined by being locked in a closet. At the end of a year she was moved to an institution for the mentally ill where she regressed even more. Through the pleas of her parents she was returned after 6 months to the Beatrice State Developmental Center.

At the Beatrice State Developmental Center it took her many months to get back to the functioning level at which she left the institution. She continues to improve, is happy, and enjoys the campus activities. Her parents and the professionals believe the structured environment best fits her needs.

For Kathy, Beatrice State Developmental Center is her home, her community. S. 2053, by closing or causing a reduction in quality programs, would be a devastating blow to Kathy.

PHILLIP ENERSEN

Phillip, now 37, was diagnosed as trainable, and he attended a parochial school for several years. His father was a prominent architect and his mother, finding no school facilities in the city for children such as her son, was the chief instigator of early community programs for the retarded. These early programs were run primarily by the parents. Mrs. Enersen has, through the years, received many high honors and awards for her over 25 years of actively working for all retarded persons.

Phillip, after attending a training school in St. Louis, went to the Holy Angels School in Shreveport, Louisiana, until his early twenties.

He returned home to take part in new community programs that had been started for adults to prepare for simple factory work. The plan was for him to live at home while he learned these skills.

Under the stress of the program, Phillip regressed alarmingly, resulting in a nervous breakdown.

After psychiatric care and some trying times for him, he was accepted at the Martin Luther Home facility, which receives Medicaid funding. He has been a resident there for 10 years and is doing well.

Because of early training, exceptionally good manners, and good appearance, professionals and his parents feel that his abilities have often been overestimated. Phillip has a friendly nature and was once preyed upon by unscrupulous persons in a laundromat.

Phillip needs, and has the right to have, a sheltered environment that gives him health, happiness and protection.

MATTHEW CRAWFORD

Matthew is 22 years old and profoundly retarded. He lived at home with 2 brothers, 2 sisters, his mother and father until age 14, when he entered the Beatrice State Developmental Center.

He pioneered a nursery school for the mentally retarded from age 3, and as the kids grew older, the program served more and more children and eventually evolved into the public high school program. Before the public sector took over the school, the parents "begged and borrowed" the money to keep it going. There were bake sales, garage sales, volunteer help, token wages for the teachers.

Matthew got along fine at home during early childhood. It wasn't until he got to be 12 or 13 that he grew increasingly apprehensive and less happy. At the same time, his brothers and sisters were at home less and there were many errands and activities which were disruptive to Matthew's peace of mind. It became apparent that Matthew needed a highly structured environment.

His IQ is not measurable since Matthew does not have the prerequisite skills to take the test; he is considered to be profoundly retarded. He has no speech at all.

Matthew is a cute little man, blond hair, brown eyes, 5'2" tall. He has a remarkable sense of humor for a severely handicapped guy; people like him. His behavior is generally good and he seems to be quite happy. The things most important to Matthew are an iron clad schedule, familiar surroundings, and familiar people. He likes rock and roll music and swimming. He is difficult to motivate because we have not discovered anything else he really enjoys doing. He takes pre-vocational training which teaches sorting and simple assembly skills, but he requires continuous prompting.

At the Beatrice State Developmental Center, he is able to move about familiar areas of the campus, independently. At home, he has to stay in his own yard. He has no fear of environmental hazards, so requires constant supervision, especially on a home visit.

Because he has no speech, his parents believe that he is safe in an institution which is always open for inspection for visitors or staff and where he cannot get lost.

Matthew's progress is evaluated yearly by his entire team, more frequently by direct staff. The team met February 6 and determined that Matthew was properly placed and should remain at Beatrice State Developmental Center.

Community Living is Seldom Integrated Living for Severely Mentally Retarded Persons

"Community" living for the retarded has been touted as the golden pathway leading to a lifetime of pleasant associations with normal persons.

Yet, within my own city, Lincoln, Nebraska, many retarded adults have little or no participation in activities with normal adults. Here is a description given to me by a Sunday school teacher of retarded person living together in a group home:

> The retarded persons in my Sunday school class have little contact with normal persons other than staff. They live, eat, play, study and work only with other retarded persons in the community. They live in group homes, with OTHER RETARDED PERSONS. They go, during the week, to sheltered workshops for RETARDED PERSONS only. In the evening they may have special classes, held for RETARDED PERSONS, or they may attend the special weekly recreational event, FOR RETARDED PERSONS; occassionally, on dates selected by the bowling alley operator, they all go bowling, using only lanes designated for the retarded group. They sometimes go to movies or other entertainment, but escorted by staff or volunteers, as they did at the institution.

Unfortunately, for those less retarded, who are allowed to go out without supervision, there is the risk of being either the victim of crime, or of unwittingly committing a crime.

Note this, from a Fall 1983 seminar on "Jail, the New Institution for the Mentally Retarded?":

> It was estimated that 700 developmentally disabled persons entered the criminal justice system in Nebraska during 1982. There are 106 developmentally disabled persons in prison in Nebraska.

This statement brings to mind the prophetic statement of a judge several years ago, when Beatrice was, by court decree, being emptied of the mild and moderately retarded.

> If you keep emptying institutions for the mentally retarded, you'll find yourselves, someday, building penal institutions instead.

For many residents of Beatrice State Developmental Center, placement in the community would mean restriction to a city block, instead of a 640 acre campus, where they had easy access to the institution's restaurant, gift shop, beauty shop, gym-auditorium-theatre combination, hospital, park, chapel, etc.

There has been a great deal of speculation, conversation and misinformation about the comparative costs of serving mentally retarded persons at the Beatrice State Developmental Center, as compared with community-based programs.

In view of this, in 1980, the Nebraska Institutions and Welfare Departments commissioned Touch Ross & Co. to do a study (which they believe to be a first study anywhere), which would give the comparative costs of caring for people with approximately the same levels of retardation in the community and in an institution. The costs at Beatrice and in the community programs in each of Nebraska's six mental retardation districts were examined.

As a result of that study,*, Touche Ross reported that costs of HIGH NEED clients were higher in the two regions containing the two metropolitan areas of the state (Lincoln and Omaha); but lower in the other regions. It is significant to note that VERY FEW high need persons were being served in those outlying regions. Nevertheless, in the two regions serving the high need individuals, cost at Region 5 (16 counties including city of Lincoln) was $21,000; in Region 6 (5 counties including city of Omaha), $23,700; and at the Beatrice institution, $19,600. In the other regions costs ranged from $9,700 to $16,800 each year.

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*See attachment

What will be the net effect of S. 2053?

Nebraska has done an exceptional job in providing community based programs. The impact on the population remaining in the institutions is significant--of a population of 461 at Beatrice State Developmental Center: 86% of the residents are profoundly or severely retarded; 175 are non-ambulatory; 65 persons are totally blind; 237 have hearing impairments, 9 being profoundly deaf; 292 of the 461 have no speech--only 58 have fairly normal speech skills; 213 are epileptic; 120 receive psychiatric care. S. 2053 would send these folks across a state which has large areas which are designated by the federal government to be primary medical care shortage areas (see attachment). The western two-thirds of the state lacks experts of all types, physical therapists, occupational therapists, speech therapists, etc.

The Joint Commission on Accreditation of Hospitals accredited Beatrice State Developmental Center, if deprived of Medicaid funds, would not be able to adhere to criteria for accreditation and would probably become a warehouse, a custodial facility only.

In Nebraska, with only one million taxpayers, we are saddled

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*See attachments

with a very high property tax, sales tax, income tax, sin taxes, gas taxes, taxes ad infinitum!

Can we really afford to discard four residential facilities for the mentally retarded? Can Nebraska taxpayers afford to build or replace complete facilities for 905 mentally retarded persons?

The present Medicaid law encourages and allows the states to bring their institutions up to modern acceptable standards of care. It also provides the states the opportunity to serve the severely handicapped in an integrated setting through use of the Medicaid waiver. A recent Supreme Court decision affirmed the rights of the state to care for the disabled in institutional settings. Right now, 25 states are using Medicaid funds in community programs through the Medicaid waiver program.

What if S. 2053 boomerangs?

With Medicaid funds phased out of the institutions, the states will have to assume the total cost. If states, having increased the mental retardation budgets to make up for the lack of federal funds to institutions, cannot afford to build new community residences, the net effect on the retarded people will not be desirable. The institutions will probably decline in quality and movement to community will slow down or stop altogether because of limited local funds!

In Nebraska, our group homes all receive title XX monies. If S. 2053 passes, these will all be "grandfathered" into the title XIX program! Again, remember that a title XIX waiver is now available for community based programs.

Please kill S. 2053!

SUMMARY

Eighty percent of the population of the nation's public residential facilities is comprised of severely and profoundly mentally retarded people--IQ's ranging from o-35. Of these residents, 43.1% have additional handicapping conditions. The most common are blindness, deafness, lack of any speech, epilepsy, cerebral palsy and mental illness. Many of these people may never walk, talk, hold a spoon, comb their hair, brush their teeth, bathe or toilet themselves.

Community placement may offer them the opportunity of independence, employment productivity and community integration but these people are unable to profit from the opportunities.

Institutions in Nebraska are designed to satisfy the various needs of the multiply handicapped mentally retarded residents. The Beatrice State Developmental Center is fully accredited by the Joint Commission on the Accreditation of Hospitals. The accommodations are ultramodern, attractive, and air-conditioned. The severely handicapped residents are protected from ordinary hazards. The swimming pool has no deep end, the streets have a 15 mile per hour speed limit. The non-ambulatory residents routinely attend church and Scouts and other activities in wheelchairs or mobile beds. If S. 2053 is enacted, 57% of the funds will be removed from this fine facility. Quality services will be replaced by custodial services only, and/or the place will have to close because state and local taxes cannot be stretched any further to make up the difference.

There are no data which prove that community placement is beneficial to the severely and profoundly retarded who are often multiply handicapped.

There are no data which prove it is cheaper to serve these severely handicapped at an integrated site.

The present Medicaid law encourages and allows the states to bring their institutions up to modern acceptable standards of care. It also provides the states the opportunity to serve the severely handicapped in an integrated setting through use of the Medicaid waiver. A recent Supreme Court decision affirmed the rights of the states to care for the disabled in institutional settings. Right now, 25 states are using Medicaid funds in community programs through the Medicaid waiver program.

With Medicaid funds phased out of the institutions, the states will have to assume the total costs. If states, having increased the mental retardation budgets to make up for the lack of federal funds to institutions, cannot afford to build new community residences, the net effect on the retarded people will not be desirable. The institutions will probably decline in quality and movement to community will slow down or stop altogether because of limited local funds!

If Medicaid funds are already available for community based programs are now being used by 25 states for community mental retardation services, then what is the purpose of this bill? Its sole purpose is to close institutions.

Kill S. 2053.

The synopsis of professional journal articles following supports the testimony here presented.

"Normalization Through the Normalization Principle: Right Ends, Wrong Means"
Author: John M. Throne
Journal Mental Retardation, October 1975, pp. 23-25.

The author's point is that the normalization principle presents the desired outcome, but the only way to obtain that outcome involves non-normal or specialized treatment procedures and specialized environments.

"Cost Comparison of Institutional and Community Based Alternatives for Mentally Retarded Persons"
Author: James C. Intagliata, Barry W. Wilder, Frederick B. Colley.
Mental Retardation, June 1979, pp. 154-156.

The authors compared the costs of care in institutions and group homes, family care and natural family. The natural family was found to be the cheapest with the group home the most expensive of the community options, only slightly less than the institution depending on the severity of disability. Professional treatment such as physical therapy was significantly more expensive in the community versus the institution.

"Cost Benefit Analysis and Mental Retardation Center Funding"
Author: Jack Bernard
Mental Retardation, June 1979, pp. 156-157.

The author discusses in a general manner the very favorable payoff to society as a whole for investing in mental retardation programs.

"New Long-Stay Patients in a Hospital for Mental Handicap"
Author: Douglas A. Spencer
British Journal of Psychiatry, 1976, Vol. 128, pp. 467-470.

The author describes the reasons handicapped individuals are admitted to long-term care facilities (e.g., behavior problems, physical infirmity and helplessness) and why long-term care facilities are the only reasonable option for their care.

"Assessments of Residential Environments for Mentally Retarded Adults in Britain"
Author: Mary Dalgleish
Mental Retardation, Vol. 21, No. 5, pp. 204-208.

The author compared the services to mentally retarded individuals from large older institutions to newer smaller hostels. The comparisons revealed that the older institutions cared for the most impaired (physically and behaviorally) and were less homelike than the new hostels. Comparisons of cost and size could not be made in any meaningful way because of the differences in client type served. The author concludes that the quality of care is dependent on more than just the physical surroundings.

"Deinstitutionalization: Too Wide a Swath"
Author: John M. Throne
Mental Retardation Journal, March 1979.

The author discusses the fallacies of the deinstitutionalization movement pointing out that families are institutions also and that research does not indicate that group homes are better or worse than large institutions. He points to the relevance of operant procedures in management, administration and training as the most productive path to pursue.

"A 50-State survey of the Current Status of Residential Treatment Programs for Mentally Retarded Offenders"
Author: George C. Denkowski, Kathryn M. Denkowski, and Jerome Mabi
Mental Retardation, Vol. 21, No. 5, pp. 197-203.

The authors investigated, via a survey, the services for mentally retarded criminal offenders. They found a few (185) beds available in community settings across the country, but they served clients with minor low frequency aggressive behaviors. The more difficult mentally retarded offenders are served in institutions (737). By 1983, the authors estimate that there will be 1070 beds available whereas as many as 15,000 beds are needed.

"Living in the Community"
Author: Sharon Landesman-Dwyer
American Journal of Mental Deficiency, 1981, Vol.86, No. 3, pp.223-334.

The author provides a very objective and articulate evaluation of service options for mentally retarded. She reviewed the literature on the pros and cons of institutional and community living. Finally, she provides four succinct and thoughtful suggestions for future development and evaluation of mental retardation services.

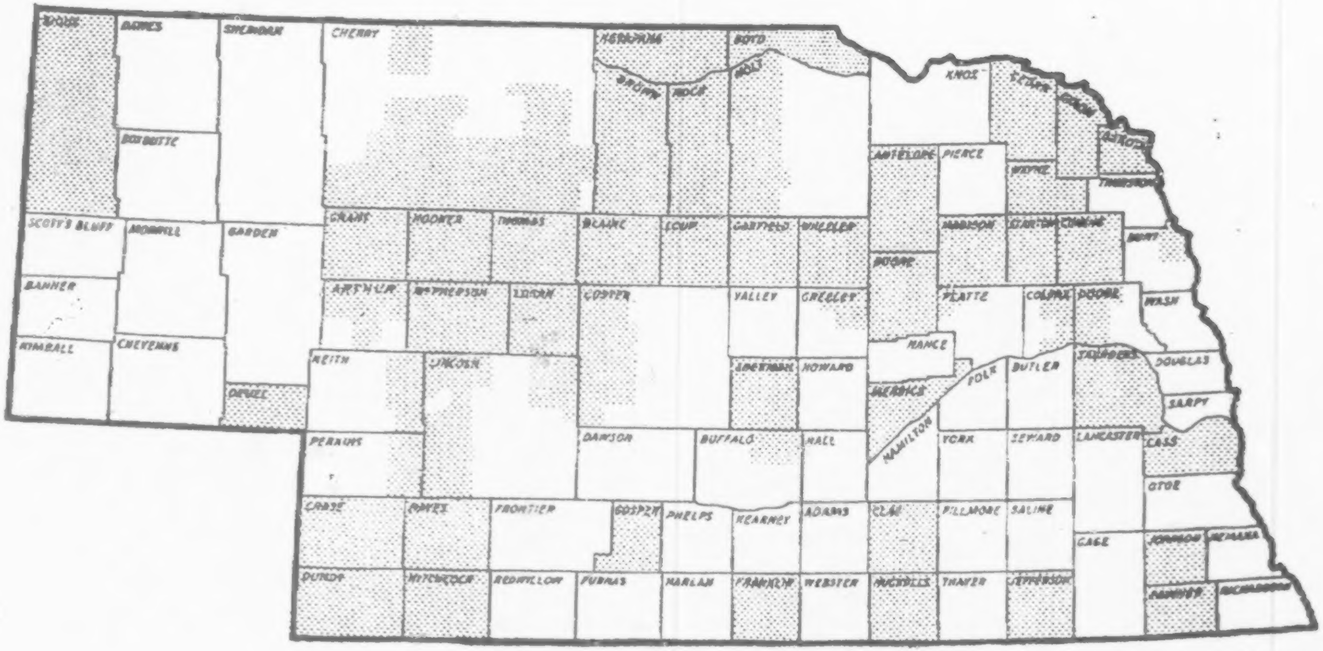
"Relationship of Size to Resident and Staff Behavior in Small Community Residences"
Author: Sharon Landesman-Dwyer, Gene P. Sackett, Jody Stein Kleinman
American Journal of Mental Deficiency, 1980, Vo. 85, No. 1, pp. 6-17.

The authors examined the commonly accepted belief that smaller (i.e., less people/fewer people) were better than more congregate living environments. This was not found to be the case. In the larger facilities there was more social behavior between the residents and reciprocal friendships than in the small facilities. Resident behavior on the whole was more related to variables such as social interaction patterns.

"Individual Community Placement of Deinstitutionalized Mentally Retarded Adults: Some Personal Concerns"
Author: Marilyn Aninger, Bruce Growick, and Kaye Bolinsky
Mental Retardation, 1979.

As the title suggests this was basically a follow-up evaluation of the effects of community placement.

PRIMARY MEDICAL CARE SHORTAGE AREAS



NOTE: Areas designated by the U.S. Department of Health and Human Services in accordance with Section 332, PHS Act.

DATE: December 2, 1982

Touche Ross & Co.

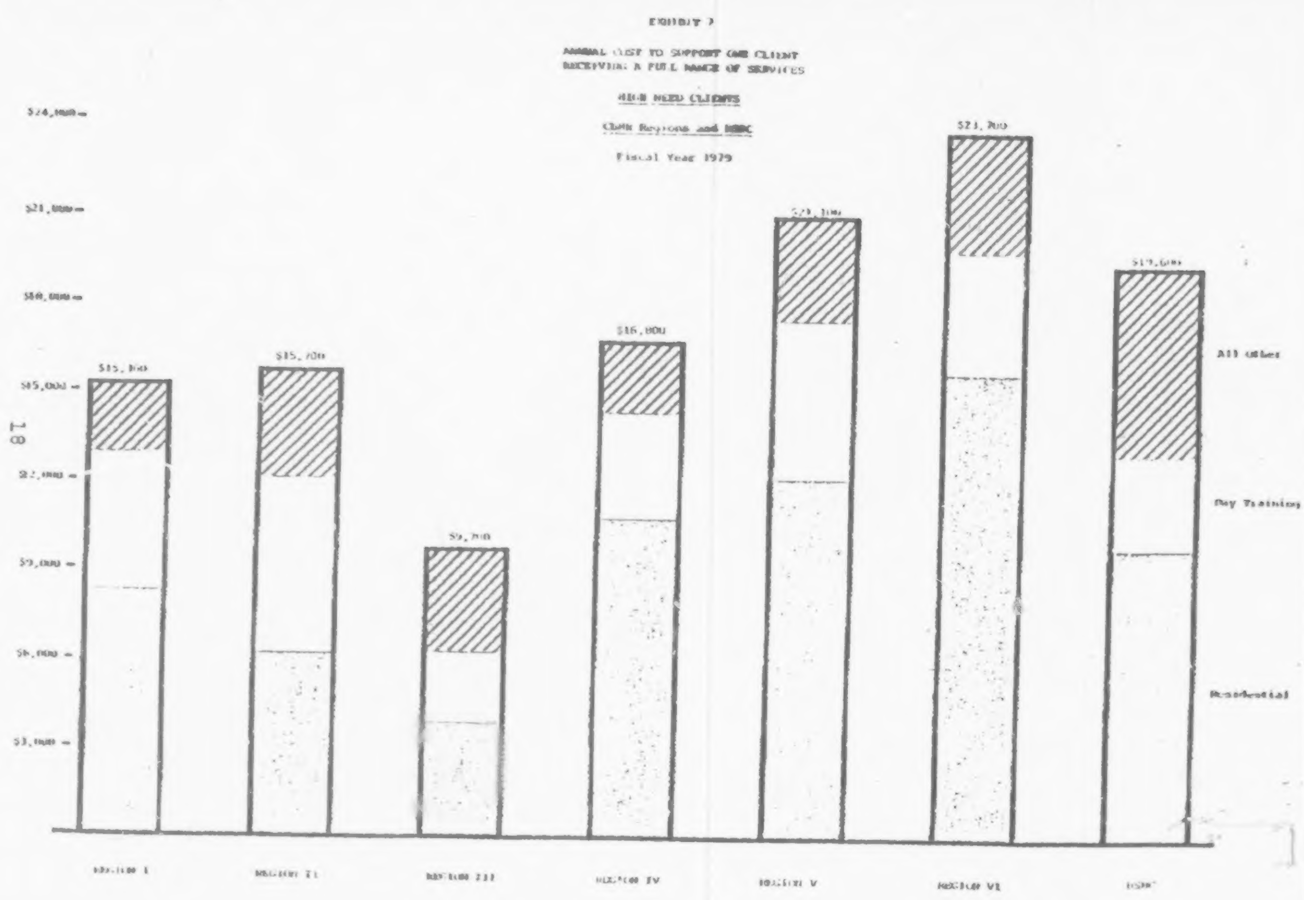


EXHIBIT 7

ANNUAL COST TO SUPPORT ONE CLIENT
RECEIVING A FULL RANGE OF SERVICES

HIGH NEED CLIENTS

[illegible] Regions and [illegible]

Fiscal Year 1979

Senator DURENBERGER. I would just note for the record that, at your request, I called Ms. Crawford and visited with her on the telephone last Friday, and I trust that we can accommodate the views of as many people outside this room and outside the financial ability of making the trip to Washington as part of this record.

So thank you very much for being here.

Senator PELL. Thank you.

Senator DURENBERGER. Our first two witnesses are a panel consisting of David Braddock, who is director of the Evaluation and Public Policy Division of the National MR/DD Expenditure Analysis project at the Institute for the Study of Developmental Disabilities in Chicago, Ill., and Karen Green-McGowan, who is a registered nurse and a consultant from Peachtree City, Ga.

Is Karen here?

[No response.]

Senator DURENBERGER. She must be caught in the traffic outside the hall.

Well, Mr. Braddock, why don't you proceed with your testimony. We appreciate very much your being here. Your full statement will be made part of the record of this hearing.

STATEMENT OF DAVID BRADDOCK, PH. D., DIRECTOR, EVALUATION AND PUBLIC POLICY DIVISION, INSTITUTE FOR THE STUDY OF DEVELOPMENTAL DISABILITIES, UNIVERSITY OF ILLINOIS AT CHICAGO, CHICAGO, ILL.

Dr. BRADDOCK. Thank you, Mr. Chairman.

I appreciate the opportunity to appear before you and the other members of the committee today. I too share Senator Exon's concerns that whatever is to come out of the introduction of S. 2053, a cautious balanced approach is the best step.

I also feel that I can best contribute to the deliberations on this important bill by primarily sharing with you information that we have recently collected and partially analyzed in relation to an expenditure analysis project that has looked at comparative community versus institutional expenditures in the United States over the last 8 years.

I believe that the fiscal record demonstrates that a major fiscal incentive to spur the development of community services in the United States is appropriate, and if but one single thing comes out of the introduction of S. 2053 I believe that it should be, and I believe that the fiscal record demonstrates that it should be, a major national fiscal incentive to spur the development of those community services.

In brief, let me highlight a few of the most interesting findings of the research we recently completed in part.

This is a line chart depicting the growth of Federal MR/DD expenditures in the aggregate as compared to the total Federal budget, both nondefense and defense components. It is contained in the written testimony that I handed out, if you don't have a good view of this chart.

In brief, since fiscal year 1980, MR/DD expenditures in the aggregate in the United States as a percentage of the total Federal budget have not grown, and for fiscal year 1984, for the first time——

Voice. Excuse me, Mr. Chairman. Could the witness please identify the page number?

Senator **Durenberger**. Page 8.

Dr. **Braddock**. The percentage of the total Federal budget occupied by MR/DD programs in the aggregate is approximately three-tenths of 1 percent of the total budget. And as I indicated, in 1984, for the first time in many years, we see an actual decline in that figure.

The second point I would like to make is with respect specifically to the ICF/MR program. Over the last 8 years approximately $12.9 billion in Federal-share ICF/MR expenditures has been issued under reimbursements for this program by the Federal Government in both institutional and community settings. Eighty-two percent of these moneys have flowed into State treasuries which were reimbursements for services in public institutions for the mentally retarded. Eighteen percent of this $12.9 billion were reimbursements to community programs and services of all varieties, shapes, sizes, and, of those, three quarters of those community programs were private ICF/MR operations.

Moving along quickly, the comparative relation between institutional and community programs is rather starkly in favor of the institutional support received by the ICF/MR program in State institutions.

In 1977 the figure was about $45 million, versus nearly $700 million in institutions; in 1984 the figure is approximately $600 million for community programs, and over $1.8 billion in institutions.

Senator **Durenberger**. You are going to have to move very quickly.

Dr. **Braddock**. All right.

Let me, then, sum up with a couple of points:

Over the last 8 years the Federal Government, through the ICF/MR program and the State governments through general fund and special fund expenditures and through title XX have spent more than twice as much in public institutions in the United States than in community services.

If State service system configurations, which display quite dominant institution-oriented characteristics, are to be shifted in a significant way, a major kind of a fiscal incentive needs to be adopted at the Federal level to encourage them to do so, if this is to happen within the next 10 to 15 years at a rate which I believe many and perhaps most professionals and parents would agree is an appropriate speed.

In closing I would like to say that I support this bill in principal in terms of the fiscal incentive. I believe the fiscal incentive proposed is too brief and believe it should be for perhaps 7 years with one renewable 5-year term thereafter.

I would also like to endorse the deeming of ACMRDD and other national accreditation standards. And in conclusion I would like to raise a bit on the negative side a concern about its litigiousness and the fact that it requires quite excessively redundant audits of State performance. Thank you.

[Dr. Braddock's prepared statement follows:]

STATEMENT OF DAVID BRADDOCK, Ph.D. ON S.2053
THE COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983

I am David Braddock, Director of the Evaluation and Public Policy Division at the University of Illinois at Chicago's Institute for the Study of Developmental Disabilities. Thank you, Mr. Chairman and Members of the Subcommittee for the opportunity to appear before you today on S.2053.

The importance of my own personal view on S.2053, however, pales by comparison with the many organized interests, parents, and professionals who will be appearing before you later today. I will therefore limit the scope of my comments to providing a brief fiscal description of historical and contemporary trends in Federal and state MR/DD expenditures, with an emphasis on the ICF/MR program. I will also try to separate fiscal facts from editorial opinion and clearly label the later as such.

This testimony has three parts. First, a few preliminary results of a nationwide analysis of Federal-State MR/DD expenditures are summarized. In Part Two, Charts illustrating some of the major points in Part One are presented. Refer to these as you go through Part One. Part Three, "Suggested Client Relocation and Facility Phasedown/Closure Guidelines" is the product of an Institute effort jointly funded by the State of Illinois' DMHDD and the Federal Government's Administration on DD and Administration on Aging.

THE MR/DD EXPENDITURE ANALYSIS PROJECT

The "Expenditure Analysis Project" is an analysis of MR/DD funding in the 50 states and by the Federal Government. In collaboration with the Council of State Governments, and supported in part by a 24-month Project Grant of National Significance from the Administration on Developmental Disabilities, the Project is analyzing the record of MR/DD expenditures in the state executive budgets of each of the 50 states for the last eight years (FY 1977 - '84). Federal Government MR/DD spending for 79 programs is being analyzed over a fifty-year period (FY 1935 - '84).

The prime purpose of the project is to develop and test a methodology for accomplishing annual or biennial updates of MR/DD spending trends in the states and nationally. Other purposes are 1) ascertaining comparative net state general fund expenditures for community services compared to institutional services funding in the 50 states; 2) projecting if or when fiscal parity has or will be achieved in each state between community and institutional services expenditures; 3) correlating growth in MR/DD state expenditures with the presence or absence of litigation, state deinstitutionalization patterns and indices of state fiscal capacity.

Analytic Procedure
The 50-State Study

The procedure being used to obtain MR/DD state expenditure data has three steps. First, we obtained enough published state executive budgets to address the period of intended analysis: FY 1977 - 1984. (Most budget documents obtained reported expenditure figures for the preceeding one or two fiscal years.) Then, each budget document was inspected for relevant MR/DD content. The relevant MR/DD sections of the budget were duplicated and filed on a state-by-state basis.

The second step involved constructing a "general state MR/DD ledger" for each state using the same terminology employed by the state in the presentation of its executive budget. Again, the ledger covered the FY 1977 - 84 time period. To make analysis manageable, initial attention was focused on recapitulating a summary of the principal state agency(ies) operating expenditures for MR/DD state institutions and community programs. This refers to the functional state agency equivalents of the MR/DD division of (usually) the Department of Mental Health and Mental Retardation. Title XX and ICF/MR reimbursement data were also obtained. Special Education and SSI/SSDI funds are excluded from this analysis at this time.

The third step, now nearing completion, consists of implementing a comparative expenditure analysis to ascertain which operating funds have been deployed in the states between FY 1977 to FY 1984 for the provision of MR/DD community services; and which funds have been deployed to fund the operation of state MR/DD institutions. The published state budgets, of course, imperfectly breakout community and institutional MR/DD expenditure figures. Therefore, the project staff have had extensive contacts with state fiscal and program personnel to obtain and verify expenditure data. This has required mail and telephone surveys of the medical assistance and social services bureaucracies, in addition to the state mental health/DD agencies.

Procedure: The 50-Year Analysis of Federal MR/DD Expenditures

A second major component of the project is an extension and expansion of my 1955-73 study of MR/DD expenditures by the Federal Government. Data, which are primarily based on agency administrative records, have been obtained from a survey of approximately 75 agency contacts throughout the federal bureaucracy. Cost analysis techniques have been applied to 79 key programs with significant research, training, service, income maintenance, and construction missions in MR/DD. A 4,000-cell federal-level spreadsheet has been developed depicting MR/DD expenditures beginning with the Works Progress Administration (WPA) institutional construction program in 1935 and coming forward up to appropriations data for the enacted FY 1984 budget.

As with the state-by-state fiscal analysis, the data have been entered into a computer and deflated into constant dollars. Data are classified according to the five-category classification system (research, training, services, income maintenance and construction). The data are also organized on a program-by-program and agency-by-agency basis. The result yields a comprehensive picture of federal MR/DD expenditures. This analysis includes a complete fiscal history of the ICF/MR program and of other major and minor funding sources in MR/DD for which the Federal Government has been and is now responsible.

SUMMARY OF PRELIMINARY RESULTS

1. DIMINISHED RELATIVE GROWTH OF FEDERAL MR/DD FUNDS
(see Chart 1)

The relative share of Federal MR/DD expenditures as a percentage of the total federal budget has not grown since FY 1981 and, for the first time in many years diminished slightly in FY 1984.

2. INSTITUTIONS AND ICF/MR FUNDING

[Eighty thousand MR/DD individuals live in 95 state institutions with between 500 and 2,000 residents. -Bruininks, 1982]

2.1 Eight-Year ICF/MR Institutional and Community Funding Trends
Most ICF/MR Funds Support Institutions
(see Chart 2.1)

During the FY 1977 - ´84 period, $12.9 billion in Federal ICF/MR reimbursements were paid-out. Eighty-two percent of these monies were deployed in support of state institutions; only 18 percent of the sum was reimbursement for community services. About three-fourths of the "community" funds were reimbursements of private ICF/MR providers; one-fourth of the community funds went for state-operated community-based ICF/MR operations.

2.2 Rapid Growth of ICF/MR Institutional Funding
(see Chart 2.2)

In the 13-year period of the ICF/MR program's operation (FY 1972 - '84), contributions of Federal ICF/MR reimbursements to the 50 state treasuries grew explosively. In 1974 ICF/MR reimbursements represented seven percent of total state-federal expenditures for MR/DD institutional services. By 1979, the Federal ICF/MR figure exceeded 30 percent and was headed higher. FY 1983 and FY 1984 ICF/MR reimbursements climbed to 43 percent of total state-federal institutional services funds. In little more than a decade, the Federal Government had assumed nearly one-half of the costs of operating the Nation's public MR/DD institutions.

2.3 State Funding for Institutions Declines in Constant 1977 Dollars
(see Chart 2.3)

State government funding of MR/DD institutions from own-source revenues has declined since 1977, while Federal ICF/MR funds have grown markedly. Since institutions are experiencing a declining census, however, resident per diem costs have increased from $35.76 in FY 1976; to $86.22 in FY 1982 (Scheerenberger, 1976, 1982).

2.4 Facility Closures: A New Trend

The convergence of normalization tenets, lawsuits, tightly constricted state budgets, and a declining institutional census has led a number of states to close MR/DD institutions. Illinois, Michigan, Minnesota, Pennsylvania and California have completed closures of one or more institutions since 1980. Additional closures are in-progress in Florida, Maryland, Illinois, Pennsylvania and other states. Several terminated MR/DD institutions have been converted to prisons.

3. COMMUNITY SERVICES AND ICF/MR FUNDING

3.1 Community Funding is Growing

Federal-share community services ICF/MR funds expended in FY 1977 amounted to $45.3 million. FY 1984 reimbursements for community ICF/MR's are projected by the states to be $640 million.

3.2 The Home and Community Care Waiver

Federal-share Community ICF/MR reimbursements as a percentage of total state-federal expenditures for community services more than doubled from 6.3 percent to 14.7 percent between FY 1977 - '80. With some assistance from the Home and Community-Based Care Waiver Program, community reimbursements were projected to be 21% of total Federal ICF/MR reimbursements in FY 1984.

3.3 The Predominance of State Funding of Community Services
(see Chart 3.3)

Excluding Federal SSI/SSDI entitlements, the states have themselves financed the vast majority of the Federal-state initiatives in community services development since FY 1977. The increasing federal reimbursements for institutional services has, arguably, freed-up state monies for community development. Federal-share Title XX (Social Services Block Grant) Funds have, however, declined since FY 1981 in unadjusted dollars and hover around the $200 million mark. Expressed in constant 1977 dollars, Title XX (SSBG) Funds have declined steadily since FY 1977.

CONCLUDING REMARKS

Over the last eight years, Federal and State governments combined spent more than twice as much money in the Institutions than in the Community. In FY 1977, $3.48 was budgeted for combined state-federal institutional expenditures for every dollar spent on community services in the United States*. This 3.48/1 ratio has been more than halved by FY 1984 to 1.47/1. Many states are undeniably pursuing major priorities in community services development today. However, the cumulative impact of many years, in fact, decades, of radically unequal ratios between institutional and community spending poses formidable fiscal obstacles in most states. Only Nebraska, Minnesota and Colorado achieved spending parity between the institutional and community service sectors over the eight-year period between FY 1977 - '84. By 1984, parity in Institutional/Community expenditures had been achieved by only seven more states: Florida; Rhode Island; Montana; New Hampshire; Vermont; Ohio; and Michigan, whose state general funds for community services grew from $14 million to $135 million between FY 1977 - 84, even in the midst of near-depression economic conditions.

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*The ratio is predicated on the following: state general and special funds; ICF/MR reimbursements; Title XX-SSBG; and various federal programs such as Developmental Disabilities, CHAMPUS, Medicare reimbursements, P.L. 89-313, etc.

S.2053, Funding Parity, and Responsible Deinstitutionalization

In my personal view, S.2053 will make a major contribution to the well-being of MR/DD people and their families if it accomplishes one thing: the adoption of a substantial fiscal incentive for states to enhance community services. It may take at least another decade, or more, to achieve fiscal parity between Institutional and Community Services on a national basis if no such ICF/MR incentive favoring community development is adopted. Fiscal parity I believe is a good intermediate, but not long-term goal for the nation as whole. The temporary five-year period for a 5 percent increase in the ICF/MR match for community placements and care, as proposed in S.2053, is definitely a step in the right direction. But it is of insufficient duration to insure the kind of smooth transition that the present fiscal imbalances of the highly institutionalized service system configurations of most states require. I would prefer a seven-year provision renewable once by the Secretary of the DHHS, or by Congressional action, for an additional five year term. I am assuming a permanent incentive would be politically untenable at this time. I hope I am wrong.

S.2053 would entail the relocation of thousands of MR/DD persons and the phasedown of institutions. The inclusion of suggested "relocation and facility phasedown guidelines" as a preamble or through administrative regulation is important. Such guidelines need to be particularly sensitive to the interests and needs of MR/DD individuals, their relatives and also of affected employees. Such guidelines would improve the appeal of this legislation to the groups who would be most affected by it. We have recently drafted a set of facility phasedown-relocation guidelines in connection with an Evaluation Division project at the Institute studying the closure or phasedown of DD institutions. I have attached a copy of these preliminary guidelines for your review. It appears as Part III of this testimony. A number of states now have extensive experience with facility phasedowns/ closures. Knowledgeable professionals from these states should be consulted by the Subcommittee.

I would also like to endorse the "deeming" of ACMRDD and other professionally recognized nationwide accreditation systems. This would promote efficiency and raise program standards.

On the negative side, the Bill strikes me as litigious and requires excessively redundant audits of state performance. It would thus not contribute to the recent intelligent Federal trend toward reducing government paperwork.

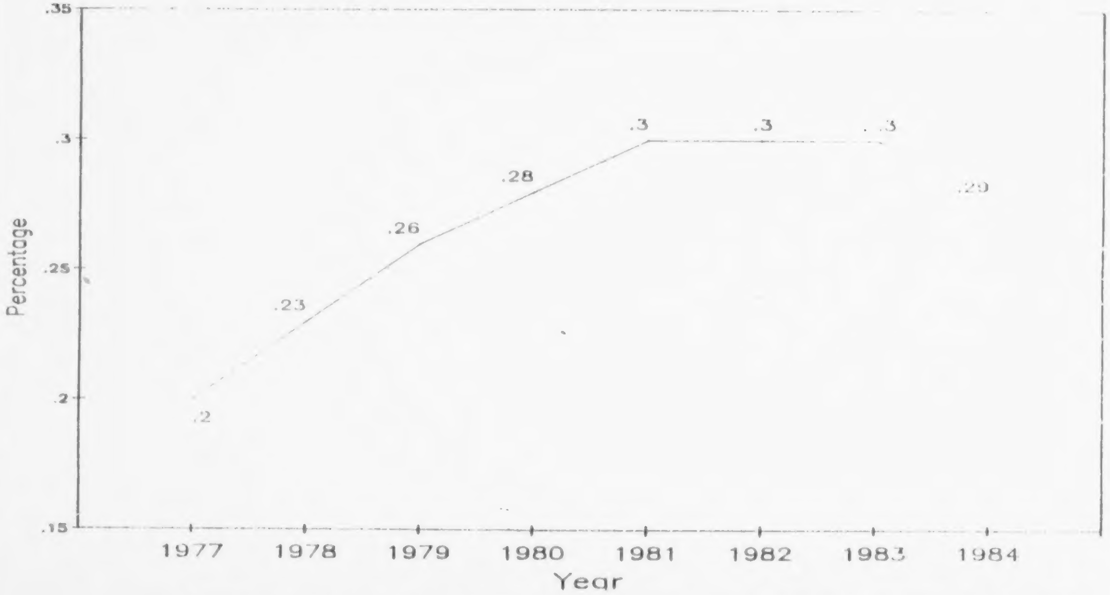
Finally, I unequivocally support a major intermediate-term or long-term fiscal incentive to spur the development of community services in the United States. I believe the fiscal record demonstrates a need for this kind of thrust. Around this single concept a consensus can and must be forged, bringing together parents, unions, associations, professionals and lawmakers, who, through responsible deinstitutionalization policies, seek simple justice and more appropriate services for people with developmental disabilities.

PART II

CHARTS

CHART 1

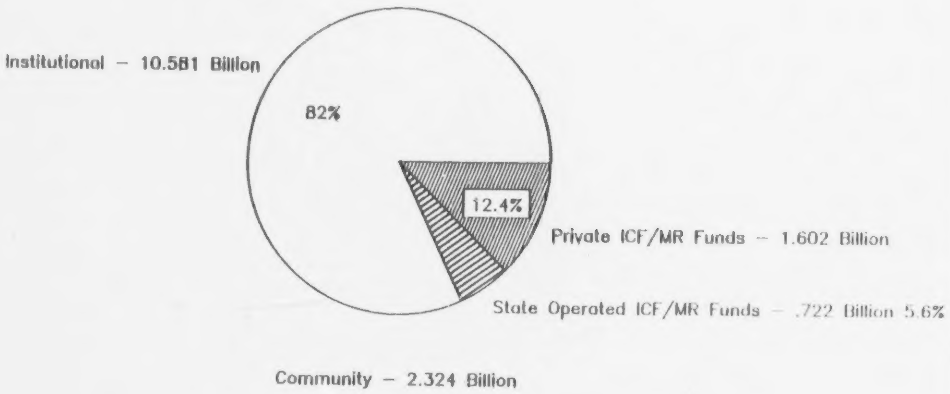
Federal MR/DD Expenditures as a Percentage of the Total Federal Budget, FY 1977–1984



Source: D. Braddock Ph.D. Expenditure Analysis Project, ISDD, U of IL at Chgo, 1984, Preliminary Data

CHART
2.1

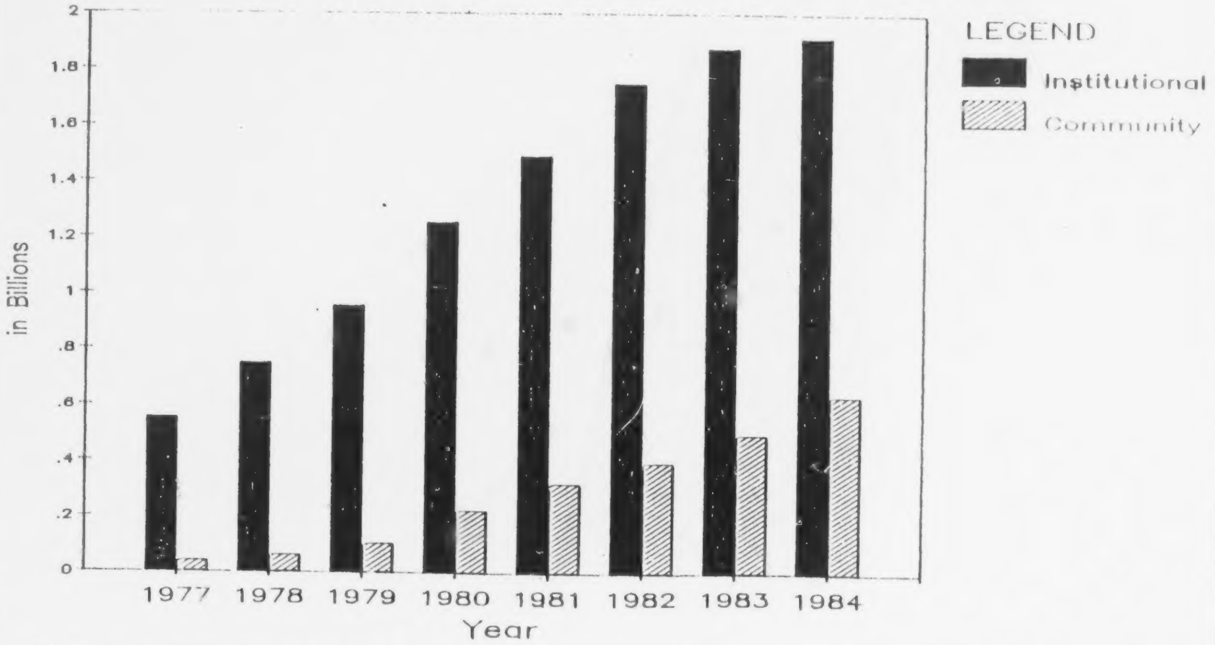
Pie Chart Depicting $12.905 Billion
Cumulative Federal ICF/MR Reimbursements in
Institutional & Community Settings
FY:1977–1984



Source: D. Braddock, Expenditure Analysis Project, ISDD, U of IL at Chgo, 1984, Preliminary Data

CHART 2.21

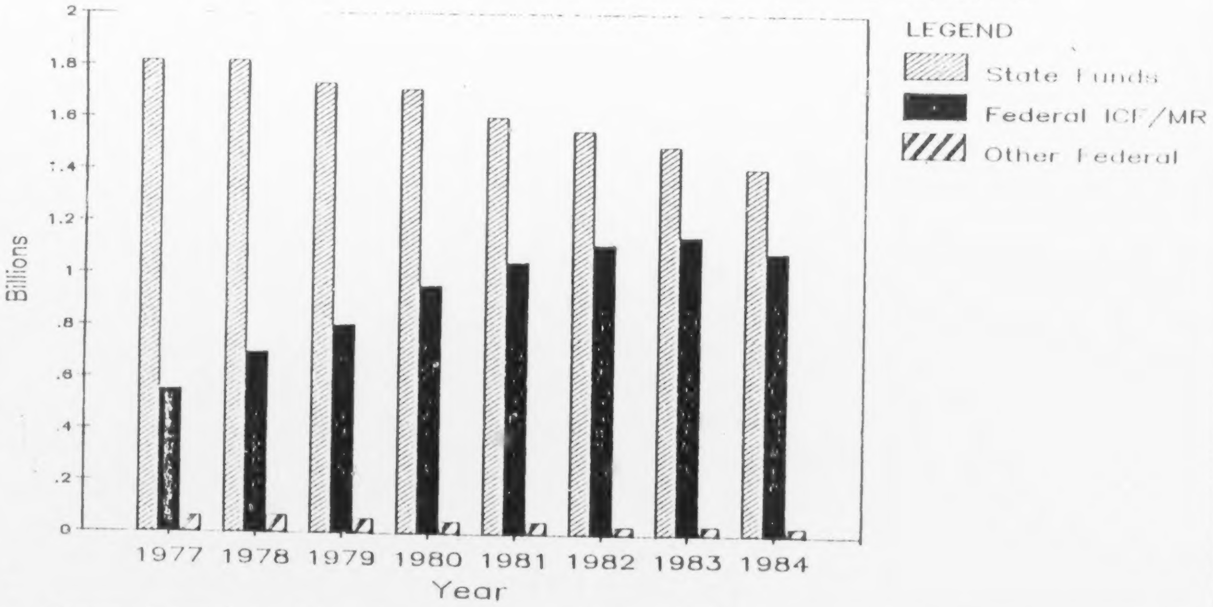
Comparative Federal Institutional & Community Expenditures for the ICF/MR Program, FY: 1977–1984



Source: D. Braddock, Expenditure Analysis Project, ISDD, U of IL at Chgo, 1984, Preliminary Data

CHART 2.3.

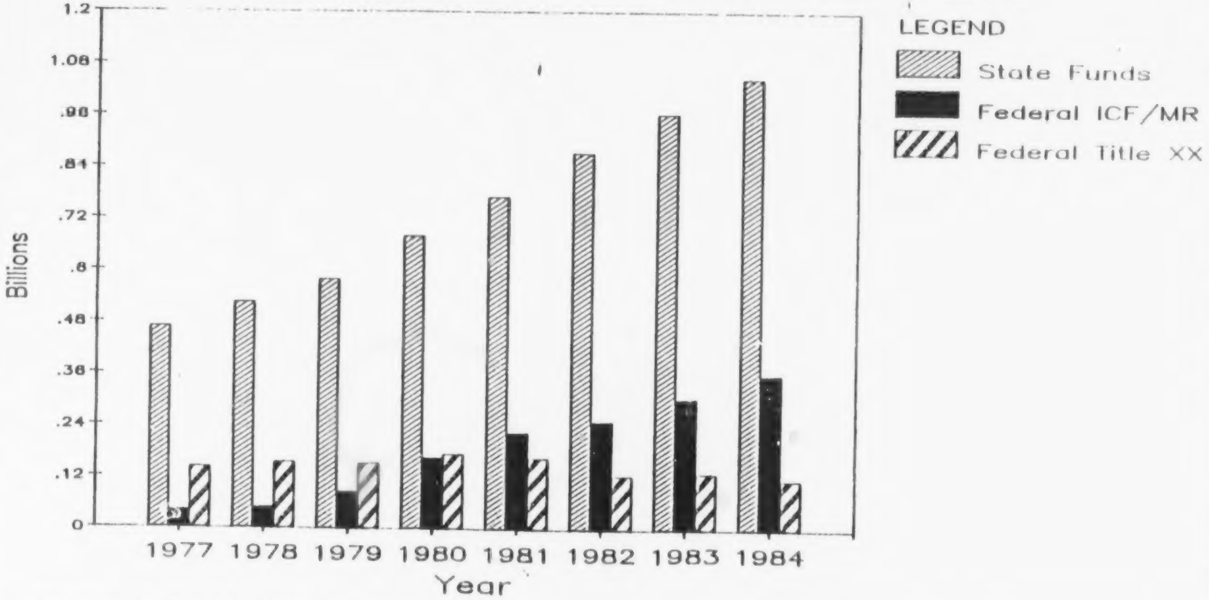
MR/DD Expenditures for Institutional Services in the United States: A Comparison of State & Federal Funding FY 1977–1984 in 1977 Dollars



Source: D.Braddock, Expenditure Analysis Project, ISDD, U of IL at Chgo, 1984, Preliminary Data

CHART 3.3

MR/DD Expenditures for Community Services in the United States: A Comparison of State & Federal Funding FY 1977–1984 in 1977 Dollars



Source: D. Braddock, Expenditure Analysis Project, ISDD, U of IL at Chgo, 1984, Preliminary Data

PART III

SUGGESTED GUIDELINES FOR FACILITY CLOSURES AND PHASEDOWNS*

●CONTENTS

1. General Management Guidelines

2. Personnel Guidelines

3. Client Guidelines
   - "Minimizing Transfer Trauma"

4. Parents/Families/Guardians Guidelines

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*From D. Braddock, T. Heller and E. Zashin. The Closure of the Dixon (Illinois) Developmental Center: A Study of the Implementation and Consequences of a Public Policy. Chicago: Evaluation and Public Policy Division, Institute for the Study of Developmental Disabilities, University of Illinois at Chicago, 1640 West Roosevelt Road, 60608; March, 1984.

Supported in part by grants from the Illinois DMHDD, the HDS Administration on Developmental Disabilities and the Administration on Aging.

1. GENERAL MANAGEMENT GUIDELINES

1.1 Short-Term Economies May Be Difficult To Achieve

Prepare the Legislature, the Governor's Office, the Bureau of the Budget and other oversight groups not necessarily to expect immediate economies from closures during the terminating fiscal year.

Our review of the public administration literature uncovered several references to facility closure costing more to implement during the terminating fiscal year than to continue present operations. A basic reason for this is the required redundant staff costs at both the sending and receiving facilities for a period of time. This axiom is true not only for closing mental institutions and juvenile facilities but also for abolishing government agencies and closing military installations as well.

1.2 Adopt a Budgetary Interchange Technique

Consider the adoption of a "budgetary interchange" technique to promote efficient facility phasedowns and supported community placements.

This budgeting technique allows the executive agency implementing closures/phasedowns to transfer funds appropriated for institutional operations in the phasing-down facility directly to community services operations. Funds follow the client from the terminating institution to the placement setting, thus facilitating an orderly transition process. Budgetary interchange is presently facilitating extensive client relocation from the Pennhurst State School, a Pennsylvania facility scheduled for closure. The approval of the legislative appropriations committee is required. Such approval minimizes the number of times the executive is required to return to the legislature for supplemental funding. Yet it need not diminish the agency's responsibility to report to and keep the legislature informed with regard to agency progress on phasedowns.

1.3 Use a Pro-Active, Participator Management Strategy

The Task Force Coordinator implementing closure/phasedown should adopt a pro-active stance vis-a-vis presenting the case for closure to concerned interests.

The strategy used by the Dixon Closure Coordinator involved initiating meetings with literally dozens of opinion-makers such as community organizations, newspaper editorial boards and television journalists, in addition to parents individually and in groups. This active attitude-shaping orientation helped to positively re-shape the climate surrounding the closure implementation.

1.4 Appoint An Ombudsman/Deputy At The Terminating Facility

Task Force Coordinator should appoint a deputy or ombudsman to act as his representative at the phasedown facility.

This individual would oversee receiving facility representatives, the screening team, and receiving facility staff when they visit the sending facility. S/he would also coordinate transfer schedules with the receiving facilities and would have authority to delay temporarily scheduled transfers. The purpose of this role would be to centralize phasedown authority on-site and to insulate the sending facility superintendent from controversy surrounding the phasedown. The latter would not be put in a position of having to choose sides between facility staff and the Department on phasedown issues. Staff complaints at the sending facility would be taken to the deputy.

1.5 Request Governor To Appoint Inter-Agency "Expediters"

The Governor should facilitate administrative efficiency by directing all state agencies involved in the phasedown to appoint an "expediter" with special authority.

The expediter from the Department of Personnel would handle transfers of sending facility staff moving to other facilities, assist with union negotiations when these were necessary, and trouble-shoot on personnel-related problems. The expediter from the IDPH would schedule surveys and negotiate modifications of standards (waivers) when the taskforce sought them. Both of these expediters would have authority delegated to them by the head of their departments to speed various kinds of approvals and paper-processing. The Capital Development Board might also appoint a similar expediter, if capital expenditures are incorporated into the phasedown plan.

1.6 Minimize Bumping

"Bumping" should be disallowed or at least minimized in the phasedown facility during the closure process.

Bumping destroys program continuity in the phasedown facility at precisely the moment residents need it most: during the later stages of a phasedown when staff and program continuity break-down. This can have deleterious effects on clients who have developed dependent relationships with staff over a number of years.

1.7 Transfer Staff With Clients

If the phasedown involves numerous transfers to other state-operated institutions, also transfer a few key staff with the clients.

The suggested guideline would be at least one key staff for each unit receiving 5 or more residents. "Key staff" refers to unit directors, shift managers, technicians, etc. In the case of the DDC closure the transfer of the (former) Dixon Assistant Superintendent to a receiving facility executive position exemplifies this practice at higher management levels.

1.8 Evaluate The Closure/Phasedown

Evaluation efforts should be initiated as soon as closure/phasedown is announced so that DMHDD Management can draw on independent perspectives during the closure process and reassure families and advocates that if clients begin deteriorating after a move, steps will be taken by DMHDD based on the evaluation to correct deficiencies.

1.8.1 Evaluate Community Support Services

If clients are relocated to community settings, a survey of the community support services in the receiving environment should be completed prior to, during and after client relocation.

The survey would assess the degree to which the DMHDD has been successful in stimulating the development of community services to support the new clients. It would also lay the foundation for the Department to justifiably seek additional revenues from Springfield to (a) augment services where they were needed and (b) develop a community services program development plan for the catchment area.

1.8.2 Conduct ACMRDD Surveys For System-Wide Facility Comparisons

When terminating DD institutions, consider requiring that they be surveyed by the ACMRDD prior to the closure decision or the closure announcement, if possible.

The performance of the terminating facility can then be compared to other DMHDD DD facilities in terms of programmatic deficiencies. The decision to close or phasedown can be justified if the ACMRDD deficiencies are extensive when compared to the median performance of all other Illinois state-operated DD facilities.

2. PERSONNEL GUIDELINES

2.1 Terminate One Unit At A Time/Minimize Internal Transfers

Close down one unit/wing/cottage at a time when possible and determine the unit/cottage closure schedule ahead of time, not during implementation, which is disruptive.

Closing down one section at a time would result in increased administrative efficiency and cost-savings. It also reduces the occurrence of internal transfers at the closing facility and keeps groups of clients and staff intact.

Prior scheduling of closures also enables better planning on the part of administrators and employees at the sending and receiving facilities.

2.2 Establish Employee Counseling Service

Establish an employee counseling and job placement service at the phasedown/closing facility as soon as a major phasedown or a full closure is announced and becomes evident to the staff.

This service would include direct person-to person counseling, workshop training, job relocation/transfer planning, resume writing and retirement planning. The final report of the Pennhurst State School and Hospital Employee Counseling Service provides a blueprint for establishing this service in Illinois. The IIDD should be consulted about developing this service.

2.3 Conduct Early And Continuing Briefings For Staff

Have a representative (an "expediter" - see guideline # 1.5 of the Illinois Department of Personnel) present comprehensive briefings to facility staff when closure or phasedown is announced.

The subject of this briefing will be to announce the initiation of the employee counseling service and to fully discuss employee rights, benefits and realistic expectations concerning layoffs, employee transfers and retirement. Identify the DOP expediter to the staff for further contact regarding specific questions. The DOP expediter would occasionally keep "office-hours" at the Employee Counseling Service Office.

2.4 Distribute Information Packets on Receiving Facility Environments

Through the Counseling Service, distribute information packets to staff describing other state and community facilities and their environs as soon after phasedown is announced as possible.

If possible, prepare a slide-tape or other A-V presentations on this topic for dual use--by families/ guardians as well as employees. The IIDD should be consulted about preparing these materials for the Department.

2.5 Adopt As Many Staff Incentives As Feasible

Consider studying in detail one or more of the following incentives to staff in terminating facilities:

2.5.1 Early Retirement

Early Retirement inducements, as has been the practice in other states phasing down facilities, such as New York.

2.5.2 Staff Retraining

Staff retraining programs for community-based services employment.

2.5.3 Extended Health Coverage

Temporarily extended Health Insurance Benefits for laid-off workers and their families throughout the first year, if the workers remain unemployed.

2.5.4 Priority Hiring Policy at Receiving Facilities

Implementation of a priority-hiring policy in the receiving facilities for laid-off staff of the phasedown facility, however, giving the receiving facility latitude to judge an employee´s performance record with the Department.

2.6 Develop/Distribute Weekly Newsletter

Develop a weekly newsletter and distribute it to staff at the terminating and receiving facilities.

This suggestion draws on the experience of the Massachusetts DMH in the closure of the Grafton State Hospital in 1973. A newsletter is a useful device to dispel rumors and improve communication between the closure oversight group and the staffs affected by the termination. Rumors abound during closures; this breeds anxiety in the staff, which is easily transmitted to clients/patients. The newsletter would include relocation time-tables, administrative policies (including changes in policy), and information about employee transfers, receiving facilities, job search, relocation of employees and their families, and places to obtain counseling.

3. CLIENT GUIDELINES

3.1 Minimize Client Transfer Trauma By Implementing an "Anticipatory Coping Strategy."

3.1.1 Close down cottages/units one at a time;

3.1.2 Keep client groups/friendships as intact as possible;

3.1.3 Minimize internal transfer of client and staff in the terminating and receiving facilities;

3.1.4 Conduct preparatory programs for clients, including site visits to the new residential setting, as desired by the clients, and in accord with their level of functioning;

3.1.5 Gradually introduce higher levels of programming at the receiving facilities upon client relocation;

3.1.6 When feasible, involve clients personally in the habilitation process and the four-level reviews;

3.1.7 Involve sending facility staff, who are most familar with the clients, in the actual move to the receiving facility.

3.2 Adopt a Four-Level Client Assessment/Placement System (Modified)

The Closure Study Staff recommends keeping the Four-Level Review Process for future closures but revising it to make it considerably more efficient. The process was time-consuming and should be condensed and simplified. Greater emphasis should be placed on economizing receiving facility staff-time away from their day-to-day responsibilities. There appeared to be unnecessary staff redundancies built into the Level II stage. A brief summary of the suggested process is presented below.

3.2.1 Initial Planning/Screening

Level I: The receiving facility representatives screen all clients subject to transfer and classify them according to special needs, e.g., behavior problems, medically fragile, special programs, etc.. (We expect the majority of clients not to fall into a special need category) A staff team from the sending facility should assist the receiving facility representatives in this process.

The Phasedown Task Force works with receiving facility superintendents (or their delegates) to determine approximate numbers and types of clients to be transferred to each receiving facility; they also establish approximate time-frames for the entire phasedown process.

3.2.2 Client Observation/Facility Assignment/Parent Notification

Level II: Working as a team, receiving facility representatives assign specific clients to each receiving facility. Representatives then observe each client going to his/her facility and prepare a data package, including the habilitation plan, which is sent to the receiving facility. This step takes place at the sending facility.

After this tentative facility assignment, Parent/Guardians are notified of recommended placement.

3.2.3 Unit Assignments/RF-SF Consultation/Special Needs Steps

Level III: Staff at each receiving facility review the packages and make tentative assignments to units. Each receiving facility sends a team with at least one representative from each unit receiving clients and specialists (as special needs of clients dictate, e.g., audiologist, psychologist, etc.) to the sending facility to meet clients and discuss their individual needs with sending facility staff. For special needs clients, the team holds a meeting with sending facility staff serving the client to discuss special issues. There is no sign-off by sending facility staff.

Back at the receiving facility, staff from each unit discuss each client they will be receiving with members of the team that went to the sending unit. Parent/Guardian may be invited to attend.

3.2.4 Appeal

Level IV: An appeal process is a necessary "relief mechanism" for closure/phasedown. There is no reason to assume that the appeal system used for the DDC closure is not appropriate for future phasedowns. This process is an appeal of the "last resort" and will be used rarely if the implementation of the first three Levels proceeds smoothly. Only one DDC client was reviewed at Level IV.

4. PARENTS, FAMILIES, GUARDIANS GUIDELINES

4.1 Consultation With Phasedown Facility's Parent's Association

As soon as closure or phasedown is announced the Task Force Coordinator or another Agency executive requests permission to address the phasedown facility's Parent's Association.

Meeting(s) should be held to explain the phasedown process and to solicit parents' assistance in integrating P/F/Gs from the sending facility and in dealing with problems that might emerge during the transfer process. It is wise to acknowledge upfront to parents at both sending and receiving facilities that the transfers may temporarily create some strains at the receiving facilities. The Department's willingness to work out solutions should be conveyed to parents. The importance of receiving facility parents in helping provide a more receptive environment for the transferred residents and their P/F/G's should be emphasized.

4.2 Involve Parents Who Have Been Through The-Process

Parents involved in the successful DDC phasedown should be invited to the initial phasedown discussions at the phasedown facility with DMH representatives.
The purpose here is to help reduce P/F/G anxieties and build support for the positive opportunities that well-planned sensitive relocation can bring to their relative. Having gone through the experience, DDC's P/F/Gs are knowledgable about the closure process and speak from a perspective uniquely sensitive to the interests and needs of the P/F/Gs in the terminating facility.

4.3 P/F/G Notification

Individualized notification of Parent/Families and Guardians (PFG) can serve to reduce anxieties and build support necessary for facility termination and client transfer to proceed smoothly. The PFG notification and consultation process is presented below and broken down into two steps: a) the letter of notification; and b) PFG Follow-up Consultation.

Immediately upon the announcement of closure or phasedown, notification letters are sent to PFGs providing the following information:

1. A rationale for the phase-down
2. The approximate time-frame
3. Positive aspects of the change
4. Types of placements that will be available
5. PFG options for alternative placements
6. Reaffirmation of the state's commitment to serve the client
7. Description of the four-level process - what will happen next
8. Name and phone number of a contact person

PFG Follow-up is continued through telephone contact, reiterating essential information in the letter of notification and soliciting PFG participation in the client transfer process.

4.4 Encouraging P/F/G Involvement

The following seven steps should be employed in the attempt to involve the P/F/G meaningfully in the process:

4.4.1 Hold Informational Sessions At SF

Invite P/F/G to an informational session at the sending facility. Representatives of the receiving facilities will make presentations (these may be Audio-Visual).

4.4.2 Open-House At RF

Invite P/F/G to open-house at each receiving facility.

4.4.3 Parent Association At RF Contacts P/F/G

Parent association at receiving facility contacts P/F/G to offer assistance, inviting the P/F/G for an individualized or small group visit to visit with staff.

4.4.4 Set-Up P/F/G Buddy-System At RF's

If the P/F/G has accepted placement, an orientation coordinator at the receiving facility designated by the superintendent requests the Parents' Association to appoint personal "buddies" for each incoming client's P/F/G. The buddy system operates during the period prior to and after placement in the receiving facility for at least 90-days or longer, at the discretion of the P/F/G and receiving facility superintendent.

This recommendation grows out of the Closure Study's Evaluation meeting with DDC/receiving facility superintendents. Although it is a simple concept, it can pay major dividends if it is implemented from the very beginning of the phasedown process.

4.4.5 Provide Financial Support To Parent's Association

The DMHDD through either the sending or receiving facility or Central Office budget, makes available such funds as may be necessary to implement active Parents' Association involvement in the orientation process. These funds are used to cover any/all out-of-pocket expenses incurred by parent-buddies in the exercise of their orientation duties. Under certain circumstances, when receiving facility parents are requested to make major commitments of time to the orientation and buddy system, remuneration through a small personal services contract is appropriate.

4.4.6 P/F/G Attends Actual Transfer If Desired

Receiving facility contacts P/F/G when transfer is scheduled and invites P/F/G to be in attendance during transfer or at receiving facility upon arrival. Parent association representative (buddy, if possible) also is present upon arrival.

Senator DURENBERGER. Thank you very much. And I want to be sure, on the record, to thank yor for the full statement, which is much more elaborate than time permits anybody's oral presentations to be today, and for all the work that you have done in this field as well.

John?

Senator CHAFEE. Thank you, Mr. Chairman.

Dr. Braddock, you endorse the legislation, with some reservations, as you have pointed out.

Dr. BRADDOCK. Yes.

Senator CHAFEE. Do you think the fiscal incentive of the additional 5 percent for the 5 years is not adequate? Is it the time or the amount?

Dr. BRADDOCK. Well, I think that the amount is minimally adequate. I think that the time is too brief to allow the kind of smooth transition that many of the States are going to require.

A lot of States are going to fight this particular provision, I think, with considerable vigor. And if this is done, a 5-year provision is not likely to have much of an impact, particularly if we spill out into the judicial arena.

Senator CHAFEE. One of the arguments we are going to have here, and it's a very legitimate argument, is the cost. Now, as I understood your testimony, you just outlined the comparison between what has been spent; but do you have some ideas as to the per-patient cost per day in the varied settings including capital costs?

Dr. BRADDOCK. Well, I have two comments I would like to make about that, and one of them is that the per-capita expenditures in State institutions has grown from $35.76 in 1976 to approximately $86 per day in 1982 in State institutions.

I know of one institution in the United States where it is $500 a day. This institution is phasing down and will be closing soon.

As the census of institutions drops, the price goes up, and I wouldn't be surprised to see a number of institutions in the United

States with per diems in excess of $100 per day, were an assessment to be done in 1984. And were an assessment to be done perhaps 5 years down the road I think we would see a proportionately much larger cost.

As far as comparative community costs are concerned, for less severely retarded or disabled individuals the savings in community services is tremendously large compared to the cost of services in an institution. As you get closer and closer to more and more medical kinds of services that are required, the savings tend to diminish, significantly so, to the point where I don't think it is possible to say with any kind of scientific certainty that it is always cheaper. I don't think that is a good basis for decisionmaking in this area. I think perhaps it might be a bit more expensive for a very, very small segment of the MR/DD population to be served in community services, but a very small part.

Senator **Chafee**. Well, thank you.

As you know, as far as I'm concerned, the thrust of this legislation is not financial. Obviously the financial realities have to be taken into account, but the thrust of the legislation as far as I am concerned, is how to best care for our retarded and disabled citizens and how to help them achieve their fullest potential.

Now, if there are savings also involved, as you have indicated, that's fine; that's all to the good.

When you developed your statistics, were you considering capital as well, the capital investment?

Dr. **Braddock**. The capital investment was considered as it related to community expenditures. It was considered as it related to institutional expenditures only insofar as it pertained to renovation costs and costs incurred as part of the annual appropriations process.

Senator **Chafee**. Obviously in most States you have at least one facility now; whether it is up to ICF/MR standards or not is another question, but at least you have something there.

Dr. **Braddock**. Yes.

Senator **Chafee**. Well, thank you, Doctor, for coming, and thank you, Mr. Chairman.

Dr. **Braddock**. Thank you.

Senator **Durenberger**. Senator Exon.

Senator **Exon**. Dr. Braddock, maybe you could clarify something for me; I refer to your bar chart which is on page 8 or 9. Do you know what I am referring to? Chart 2.2 or 22?

Dr. **Braddock**. Yes.

Senator **Exon**. "Comparative Federal Institutions and Community Expenditures for ICF/MR's."

If I understand that correctly, that is the black line being the amount of Federal funds that go to the institutional programs, and the checked line is the percentage of the Federal money that goes to community-based programs. Is that correct?

Dr. **Braddock**. That is correct.

Senator **Exon**. Now, let's back up to the pie chart, the first chart that you showed. I guess I don't quite understand that.

It says "State-operated funds" down here. Is that all of the State money that is put in by all of the States?

Dr. BRADDOCK. Yes, sir, it is, but only as it pertains to community programs with ICF/MR components.

Senator EXON. Well, let me phrase the question this way, then: This is entitled "Pie Chart Depicting $12.9 Billion Federal Funds," right?

Dr. BRADDOCK. Right.

Senator EXON. If there is $12.9 billion in Federal funds, and I am sure that is accurate, how much State and local funds are being put in at the same time? Do you have that information?

Dr. BRADDOCK. Yes, sir, I do.

Senator EXON. Is that in your written testimony?

Dr. BRADDOCK. Some of it is. There is a table that I didn't get to mention that I will address your attention to, 2.3. Just turn the page and you will see a chart that deflates everything into 1977 dollars. And the hash-marked bar shows the fact that State funds supporting institutions in the United States are actually declining in constant dollars between 1977 and 1984, rather consistently.

The dark bar represents Federal ICF/MR expenditures, and these funds from 1977 to 1983 increased consistently, and in 1984 for the first time showed a very slight decrease; however, the ICF/MR Federal-share component of the State institutional budget is about 43 percent. Most of the remainder would be State support.

Senator EXON. I guess what I would like to have—and maybe some of the other witnesses could provide it, just for our education on this—if the Federal Government is spending $12.9 billion, do we have a similar figure for the total being spent by State and local facilities? If we had that, it would be helpful, I think.

Dr. BRADDOCK. I can give you that figure right now: The figure in the aggregate—see, the $12.9 billion figure is for the entire 8-year period.

Senator EXON. Yes.

Dr. BRADDOCK. The figure in terms of State funds is $17.7 billion. So the States still provided the majority of support for State institutions. But in the span of less than a decade the Federal Government has assumed nearly one-half of those costs in terms of these reimbursements as a percentage of total institutional expenditures by State and Federal Governments.

Senator EXON. Well, what are you saying, Dr. Braddock, then? You are saying that you feel it would be more fair and equitable to provide and mandate a larger share of the Federal grants for community-based programs? Is that the main point that these charts are trying to depict?

Dr. BRADDOCK. Well, the point that I am making is that over the last 13-year history of the ICF/MR program the Federal Government has come to the aid of a situation of literally a national disgrace in our institutions and has helped many of these facilities to become in part reformed.

I think that we are at a turning point in the history of services to the mentally retarded and other disabled people in this country and that it is appropriate to take a second look at the way in which the volume of these funds are indeed being allocated.

Senator EXON. Thank you, Dr. Braddock.

Senator DURENBERGER. Thank you.

Let me clarify one of these money questions, so I can get to other questions, Doctor.

It would appear to me, in looking at your charts, that what has happened over the last 8 years covered by your charts is that the Federal Government has carried an increasing share of the cost of institutional care. You point out in your testimony that the State funding for institutional care was going down, because the States, at their initiative in many cases, were starting to move their financial commitment into community based services.

Dr. **Braddock**. Yes, precisely.

Senator **Durenberger**. Is that sort of a picture of what has been going on out there?

Dr. **Braddock**. That is an accurate statement.

The last chart in the group of charts, in fact, indicates the degree to which States are carrying the burden in State own-source revenues to support community services. And I suppose this is the bottom line of my testimony, and that's that if States wanted to enhance community-based service systems, they have had to do so primarily through SSI-SSDI entitlements and State general fund expenditures.

Title XX, interestingly, has actually declined rather steadily since 1977 in constant dollars in terms of the social services funds that were being allocated under its reimbursements for community services.

So the States, arguably, have been able, by pulling out of some institutional support, to spend more money on community services. And we see some of this happening. The problem is that the fiscal imbalance between community and institutional spending has gone on for so long and it was such a large imbalance for so long that, in the absence of a more forthcoming and vigorous incentive of some type we are going to be waiting quite some time before we have comprehensive community-based services——

Senator **Durenberger**. But to get back to my question which is what we are here for. John says we are here to provide the best quality of care for every one of these individuals, Jim said the issue is quality, not size; you talked about needing a national fiscal incentive, I presume—to achieve that goal.

Now, it strikes me in looking at those figures, that the States, meaning the folks who are closest to the people out there, are the ones that have taken the lead in deinstitutionalization, normalization, whatever you may want to call it.

And so my question of you is the degree to which there is a relativity between Government-based financing and quality of care. And I think I need to know—as you ask me to come up with a national fiscal incentive—whether that means just a new pot of Federal medicaid money going out there, is it a pot of money going out with a set of mandates, or is it some other possible form of public financing that puts incentives perhaps much closer to home, in the hands of local governments, in the hands of communities, or in the hands of persons and their families that are experiencing development disabilities?

Dr. **Braddock**. That question is difficult for me to answer in a brief period of time, but I think it is a national fiscal incentive in the ICF/MR program, with a set of mandates, in brief.

I think it is also a review and rethinking of numerous Federal programs that have disincentives in them that encourage States and communities to push individuals out of communities and into State institutions.

One of the problems that we have in Illinois is that we did not build a single MR/DD institution within Metropolitan Chicago until 1973; therefore, most retarded people were literally extruded 100 miles and 140 miles away to the large State institutions. So, Illinois is still paying the price of not having even provided institutional services near major population centers.

So I think you need to look at more than simply the ICF/MR program, but the ICF/MR program is some 40 percent of all Federal expenditures in the MR/DD area.

So, as goes the ICF/MR program, probably so will go the critical mass of services toward retarded people in the United States.

Senator **Durenberger**. But, in effect, the bottom line of this bill as I read it says, "Use Federal money to get Federal mandates, both of them landing on an institutional provider." Nothing here says, "Perhaps the money ought to go to the individual involved or someone representing the individual involved to help make the choices."

So in effect we are saying, "The money used to go to big State institutions, and so that's where we sent our people." Now we are starting to build another delivery system by sending money to the providers.

Have you looked at this issue of whether we should just continue to try to improve the quality by sending money to institutions only and then picking the people who will go to what institution?

Dr. **Braddock**. No. As I understand the way the bill is structured, it would also impose an expectation upon private providers of service with facilities larger than stipulated sizes in addition to institutions. It is not strictly focused on State institutional programs but rather on ICF/MR facilities outside the institution that are larger than 16 beds.

Senator **Durenberger**. But the decision about who goes where and the responsibility——

Dr. **Braddock**. Well, on that particular topic I am not sure I would prefer to give an answer off the top of my head. I don't like to think in terms of an ideal world; I would rather deal in terms of fiscal facts and parts of the legislation that I understand in some detail.

Senator **Durenberger**. Well, perhaps some of the others who are going to testify can try to think in this sort of an ideal world, and maybe you can with a little time. It may be unfair to pop that on you here, but because of your background I would like some testimony in the record on that issue.

Senator **Exon**. Dr. Braddock, thanks for coming. I am going to look through your material, because I am very much interested in this.

Since I am for both types of facilities and improving both, would it be fair to say that your testimony is to represent that it is your belief that the measure before us essentially would mandate more of the Federal funds, whatever they are, go to community-based facilities and at least take that portion of the decision away from local officials? Is that a fair paraphrase of what you are saying?

Dr. **Braddock**. It is my understanding that the bill as it is written—but I would want others who are dealing of the technicalities of the language of the bill to determine whether or not a mandate is required—certainly the intent of the bill is to phase down and phase out State institutions in the United States. I think this is a primary purpose, and to provide alternative services in community settings.

Just by way of summation, I think, in 1977 we had one State in the United States that provided at least $1 of care in the community for every $1 in the institution, and that State was Nebraska. And over the last 8 years only three States, if you total up all of their institutional and community expenditures excluding SSI and SSDI actually spent a little bit more money in the community than they spent in the institution. And those three States were Nebraska, Minnesota, and Colorado.

Now, as of 1984 we have an additional seven additional States that are spending an approximate one-to-one parity, which I think is a reasonable intermediate-term goal—not necessarily a long-term goal but an intermediate-term goal. Those seven have several members on the committee representing them, including Rhode Island, Florida, New Hampshire, Vermont, and Michigan.

I think what is important to recognize is that a number of States have been able to initiate major community services priorities, and Nebraska certainly is one of them that is probably going to be the least impacted by any compromise type of legislation that comes out of S. 2053, in my view.

Senator **Exon**. Thank you for being here, and I appreciate your testimony. I am not sure that I agree with your conclusions, but you are an expert, and that's what we need. Thank you.

I would like it to be known, so that there is not any more confusion, I am not a member of the committee, and if I were I would be sitting on the other side of the table. I just wanted to clarify that.

Senator **Chafee**. Well, we are glad to have you on this side of the table, and it was good of Dr. Braddock to make some nice comments about Nebraska, wasn't it?

All right. Thank you very much, Doctor.

The next panel will be Barbara Matula, Dr. Howse, Senator Bloom from Illinois, Dr. Carl, and Mr. Gunther.

Will those panelists please come to the podium?

Everybody's statement will go into the record, so there is no need to read your statements in full. We have quite a few witnesses and want to give everybody a chance. So if we start right off, you can summarize your statements. Everybody has 2 minutes. There will be a chance for questions to draw you out.

So, Ms. Matula, if you will start right off.

STATEMENT OF BARBARA MATULA, DIRECTOR, DIVISION OF MEDICAL ASSISTANCE, NORTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN RESOURCES, RALEIGH, N.C., ON BEHALF OF THE AMERICAN PUBLIC WELFARE ASSOCIATION

Ms. **Matula**. Thank you.

I am here representing the State Medicaid Directors Association, and, as you can imagine, the issue of caring for the mentally retarded is an issue of considerable concern to us.

While deinstitutionalization isn't new to the States, I think the most important recent impetus to that has been the waivers which allow us to expend medicaid funds in home and community-based settings rather than in the traditional institutional settings.

Summarizing very quickly, I think that our primary concern with the bill is that it severely limits the variety of settings in which the disabled individual could receive treatment.

We believe that providing each recipient with the most appropriate care does not mean, always, providing community-based care.

An individual, we feel, should not arbitrarily be moved from one type of setting to another unless he or she is going to benefit from this, and I think you have experts in the field who could tell you better than I that not everyone will benefit from a community setting.

Most importantly, as State officials, we do not feel that the Federal Government should be prescribing specific sizes and locations for each State.

We feel that we do have the experience now in the medicaid program, though it is only 2 years under our belt, of providing care and incentives for home and community-based waivers, and I think if my testimony led to one conclusion it would be that we strengthen that area.

This is very new. We have moved slowly. We didn't want to repeat some of the old mistakes and the old charges of "dumping" patients; this was not our intent. But the waivers, over half of which have been particularly for the MR/DD population, I think need to be strengthened. Perhaps we should remove the idea of "waiver" and make this a State option, that the medicaid dollars can follow the patient to the lowest appropriate setting for his or her needs.

We don't want to undermine the family and natural community support structures; we have some concerns that the bill might unintentionally do that.

I would think that if I can beat my limit I can give my time maybe to someone else, and I would be happy to do so.

Senator CHAFEE. All right. Well, thank you very much, Ms. Matula.

Dr. Howse.

[Ms. Matula's prepared statement follows:]

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TESTIMONY OF
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FOR THE
SUBCOMMITTEE ON HEALTH
COMMITTEE ON FINANCE
U.S. SENATE

HEARINGS ON THE COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983

February 27, 1984

Mr. Chairman, members of the Subcommittee, good afternoon. I am Barbara D. Matula, director of the North Carolina Division of Medical Assistance and current chair of the State Medicaid Directors' Association.

I come before you today to present the views of state Medicaid directors on the issue of providing care to the mentally retarded and developmentally disabled, and specifically, our views on the Community and Family Living Amendments of 1983 (S. 2053).

As this Subcommittee is well aware, the Medicaid program pays for a large part of all the long-term care services in this country. About half of the money spent on nursing home care comes from Medicaid. This accounted for $13 billion in FY 82, of which $3.6 billion was for the care of recipients in intermediate care facilities for the mentally retarded (ICF/MR). The issue of caring for the mentally retarded and the developmentally disabled, therefore, is one of great importance to all state Medicaid directors.

The bill before the Subcommittee today, S. 2053, is intended to reduce, over a period of several years, the number of severely disabled people residing within institutions. The policy of deinstitutionalization, in general, is a good policy, and one which states have pursued now for well over a decade. In the last two years, deinstitutionalization has been advanced within Medicaid by the widespread use of waivers to provide home and community-based care. Approximately half of the 100 waiver applications that have been submitted by states focus specifically on mentally retarded/developmentally disabled individuals. The move to deinstitutionalize has been viewed by both state administrators and health professionals as a step forward in providing the most appropriate care for the handicapped.

It appears, however, that some misunderstanding has arisen regarding the states' efforts to move or keep the disabled out of institutions. S. 2053 seems to presume that states still are financially biased toward institutionalizing Medicaid recipients and that the existence of this bias will only disappear if federal funding to institutions is stopped. We disagree with this presumption. While we concur with the bill's general goal of furthering deinstitutionalization, we believe that the policies it lays out are based upon incorrect premises regarding current state activities and the best treatment setting for each disabled person.

Our primary concern with S. 2053 is that it would greatly limit the variety of settings in which severely disabled individuals could receive treatment. Providing each recipient with the most appropriate care does not mean providing community-based care in every instance. An individual should not be moved from one type of setting to another unless he or she would benefit from the move. However, it appears to us that S. 2053 would force states to provide all Medicaid services to severely disabled individuals in a community-based setting, even through this may not always be best for the recipient. Some disabled people need the type of intensive, round-the-clock care that can only be provided efficiently in an appropriate institution. We do not believe the federal government should be in the business of prescribing uniform sizes and locations for the provision of care. These determinations are best left to the states, which now have the experience and the incentive under Medicaid to provide the various types of care needed by the disabled.

A serious concern can also be raised about the cost-effectiveness of a community care mandate for the severely disabled. We believe that S. 2053 could lead to increased cost per day in providing care to many Medicaid recipients and would almost certainly lead to increased total costs. There is an underlying assumption that community-based care is less expensive, on average, than institutional care. However, if intensive care is provided to individuals in several small settings, rather than in one large setting, there could be significant inefficiencies. Qualified professionals to provide care and rehabilitation to disabled individuals are in relative short supply. Aside from the cost of recruiting and training the large number of new professionals that would be needed, it is doubtful that having them available in each community facility would be cost-effective, especially given the other legitimate demands on the limited health and social care resources we are willing to pay for in this society. Thus, community, facilities, as defined in S. 2053, would not always be able to sustain adequate staff or equipment for those most in need without becoming prohibitively expensive. As an example, in North Carolina we have found group homes to be as expensive, or more expensive, on average as large institutions.

Regarding eligibility and cost, it appears to us that section 6 of the bill would significantly increase the number of persons eligible for Medicaid, and therefore, would significantly increase the total expense of the program. Under home and community-based care waivers, states are using waivers to remove mentally retarded individuals already residing in institutions and place them in the community. The liberal eligibility guidelines suggested by S. 2053, however, would lead to coverage for many individuals, currently in the community, who are being cared for by family and friends. While undoubtedly some of these people deserve additional assistance, we believe it would be a mistake to significantly interfere with the natural support network in the community. That network needs reinforcement, not replacement.

One further concern with the bill is the impact on patient and family rights. If enacted, S. 2053 would severely limit the choice of treatment centers available to individuals and their families. Although this may not be the bill's intent, it would appear to be its consequence. S. 2053 does allow for a hearing process in which individuals and their families may appeal for care in a larger institution. But the result would be to put the state at risk for financing that care for those whose appeals are successful. It seems to us perverse to remove all federal funding for large institutions, yet at the same time acknowledge, through the establishment of a fair hearing process, that larger institutions may be the appropriate setting for care and treatment.

In the interest of addressing the goals of the bill, but avoiding some of the problems it would create, we offer two observations:

First, the states are currently capable of carrying out the process of deinstitutionalization for those individuals who would receive more appropriate care in a community setting. The states have been pursuing this policy for more than a decade and the activity has recently been enhanced by the home and community-based care waivers program. If there has been a concern on the part of the mentally retarded and their families, it may be that the process is not proceeding as fast as some would like, but it has been proceeding in the careful manner necessary to avoid costly mistakes.

Second, the goal of deinstitutionalization would be benefited most at this point, if home and community-based care services were made a state option, rather than a waiver program. The states have acted responsibly and prudently under the waiver program. There is no reason to believe this would change if home and community-based services were made a less cumbersome state option instead. An option would avoid the delays and uncertainties that accompany the waiver process, and would, therefore, foster the same state efforts to deinstitutionalize that the drafters of S. 2053 seek. States would still need the flexibility to waive statewideness and comparability to run an effective program, but this, too, could become a state option.

In conclusion, let me reiterate that state Medicaid directors support a policy of deinstitutionalization, but such a policy must acknowledge that optimum care for the individual is contingent on maintaining a variety of treatment settings. To the extent this option is constrained by federal statute or regulations, those in need will suffer.

Thank you for this opportunity to present our views. I would be happy to answer any questions you may have.

STATEMENT OF DR. JENNIFER HOWSE, DEPUTY SECRETARY, OFFICE OF MENTAL RETARDATION, PENNSYLVANIA DEPARTMENT OF PUBLIC WELFARE, ON BEHALF OF THE NATIONAL ASSOCIATION OF STATE MENTAL RETARDATION PROGRAM DIRECTORS, INC.

Dr. HOWSE. The State directors of mental retardation gladly accept the time given by the State medicaid directors.

Senator CHAFEE. I am not sure she specifically offered it to you, but you are the first one in line, so you take it.

Dr. HOWSE. Thank you so much, Senator. [Laughter.]

I am here representing the National Association of State Directors of Mental Retardation Programs. There are 50 of us. We collectively represent services to over 500,000 mentally retarded citizens across this country.

The national association supports the development of a comprehensive system of community-based services for developmentally disabled persons in each State; however, we oppose the enactment of S. 2053 in its present form. I will give you 11 quick reasons why we oppose the bill in its present form, and you can read them more indepth in the testimony that we have presented to the committee.

The 11 reasons are:

One, we feel that the bill as constructed would ignore the significantly different problems facing the 50 States today and ignore social, demographic, political factors, et cetera, that have to be taken into account.

Two, we believe that the bill would require States to absorb the unamortized portion of renovations and capital improvements to existing State facilities.

Three, the bill doesn't offer any assurance of the continued availability of Federal funds to support the contemplated expansion of community services.

Four, we believe that it could cause a deterioration in the quality of service in the very facilities that are being phased out over the proposed 10-year period of time.

Five, the bill does not provide reimbursement for staff training, which is a critical component of developing a quality service in the community.

Six, we believe the bill would complicate the already-difficult task of dealing with neighborhood resistance to the development of community services.

Seven, we believe the bill would increase the risk, of developing substandard community programs based on the mandated schedule, which for big States is a very tough schedule indeed.

Eight, it would require the expenditure of billions of dollars in capital outlays for community programs, to construct them in a fashion or renovate them in a fashion that is appropriate and fire safe.

Nine, the bill would have a rather substantial impact on institutional employees, and does not appear to provide the States much relief in that respect.

Ten, the bill, I believe Dr. Braddock mentioned and I certainly agree, is unusually litigious in its nature; it actually invites litigation.

Senator CHAFEE. Do you have these items numbered in your testimony?

Dr. HOWSE. Yes, sir. They are numbered by letters of the alphabet in the testimony.

Senator CHAFEE. Starting on page 7A? A is one?

Dr. HOWSE. Yes, sir, and summarized in considerably more detail.

Eleven, the last criticism that we have of the bill, Senator, is that we believe that it places too much authority in the hands of residential service providers in terms of managing services.

Another concern that we have is that the bill, as it's written, would vastly expand the number of eligible clients, and therefore it would expand the Federal and State costs involved in providing services. Also we think the reimbursable services in the bill as it is presently constructed, are defined too broadly.

This all might sound as if we have enormous opposition to the bill; however, that's not true, Senator.

Senator CHAFEE. Outside of that, you support the bill. [Laughter.]

Dr. HOWSE. These are very practical considerations. We think you have been enormously statesmanlike, and you are very timely in your efforts and the efforts of this committee to substantially reform the use of medicaid services and funding to support the direction of community-based services. And indeed, I am sure you will find, from examining testimony, that the majority of States in this country have gone in the direction of moving their medicaid dollars into community services.

Our colleague, the North Carolina State director of medicaid, mentioned the waiver program. We have an alternative. It is simply a modification of the bill as you have proposed it. We would like very much for the committee to consider this alternative along with other alternatives that I am sure will be brought up today.

Our alternative simply would be to legitimize the existing waiver authority in such a fashion that there would be a statutory modification so that States could actually receive financing for home and community based services by making those services a part of the State medicaid plan. States could chose to do so; there would be certain strings attached to the Federal commitment. None of us believe—despite your good intentions—that we receive funds without any obligations in return.

But the obligations would include a multi-year plan; States would set criteria, schedules, specify ways that interagency cooperation would be achieved, and the like.

In short, we hope that the fact that there is some stiff opposition to the bill does not result in throwing out the baby with the bathwater. We do think that the time is right for redirecting medicaid into community based services.

We think that alternatives that prescribe a way for that to occur are very timely, and believe and urge that the committee find a legislative vehicle to achieve the redirection of medicaid dollars, and to redirect Federal policy and Federal financing towards community based services.

Senator DURENBERGER. Thank you.

[Dr. Howse's prepared statement follows:]

Highlights of Testimony
on the
Community and Family Living Amendments of 1983
(S. 2053)

National Association of State Mental
Retardation Program Directors, Inc.

February 27, 1984

- NASMRPD supports the development of a comprehensive system of community-based services for developmentally disabled persons in each state. However, we oppose the enactment of S. 2053, in its present form, for the reasons outlined below.

- The establishment of a fixed national schedule for phasing-out federal Medicaid support to all larger institutions serving chronically disabled, non-elderly recipients would: (a) ignore the significantly different problems facing the 50 states and, thus, fail to account for the unique social, demographic and political factors each state must contend with in its efforts to achieve permanent systemic reforms; (b) require many states to absorb the unamortized portion of institutional renovation costs, previously mandated under federal ICF/MR regulations; (c) offer no assurance of the availability of federal funds to support the contemplated expansion in community-based services; (d) cause a deterioriation in the quality of services in facilities scheduled to lose Medicaid support; (e) require the states to provide staff training service not reimbursable under the Act; (f) complicate the task of dealing with neighborhood resistance to the establishment of community-based facilities; (g) increase the risk of developing substandard community programs; (h) require the expenditure of billion of dollars in capital outlays to construct appropriate, fire safe community residences; (i) place states in the double bind of trying to meet the legislation's institutional depopulation goals while at the same time cushioning the impact on institutional employees; (j) afford the states inadequate protection against devisive, time-consuming litigation; and (k) place too much authority in the hands of residential service providers.

- S. 2053's proposed eligibility standards also would create new inequities and vastly expand the number of eligible clients as well as the federal/state cost of providing long term care services under Medicaid.
- Reimbursable services are defined too broadly in the bill and, consequently, would extend Medicaid funding to previously excluded areas of programming.
- As an alternative to S. 2053, NASMRPD supports the following revisions in existing law:
    * Permit states to offer "home and community-based services" as an optional coverage under their Medicaid plans for recipients severely disabled since childhood who otherwise would require long term care services in a Title XIX-certified institution.
    * Require, as a condition of approval of a community care waiver request or a state plan amendment after July 1, 1985, that a state: (a) offer home and community care coverage as an optional Medicaid service no later than July 1, 1990; and (b) implement a ten year

plan to minimize the number of developmentally disabled recipients inappropriately placed in large institutional settings.

* Increase the federal Medicaid matching ratio for home and community care services by five percentage points above the state's normal share of Title XIX costs.

* Authorize states to cover pre-vocational services for eligible, non-elderly disabled persons as part of a home and community care service program, under certain specified conditions.

* Limit the Secretary's authority to place restrictions on the manner in which average per capita expenditures are calculated for purposes of approving a home and community care waiver request or the proposed optional state plan service discussed above.

STATEMENT OF TESTIMONY

The Community and Family Living Amendments of 1983

H.R. 2053

Respectfully Submitted

to the

SUBCOMMITTEE ON HEALTH
SENATE COMMITTEE ON FINANCE

The Honorable David Durenberger, Chairman

by

Jennifer L. Howse, Ph.D.

Deputy Secretary for Mental Retardation
Office of Mental Retardation
Pennsylvania Department of Public Welfare

speaking on behalf of the

National Association of State Mental
Retardation Program Directors, Inc.

February 27, 1984

I. Introduction

The membership of the National Association of State Mental Retardation Program Directors consists of the designated officials in the fifty states and territories who are directly responsible for the provision of residential and community services to a total of over half a million mentally retarded children and adults. As a result, we have a vital stake in the evolution of federal Medicaid policy.

According to statistics compiled by the Health Care Financing Administration, federal-state Medicaid payments on behalf of 124,600 residents in intermediate care facilities for the mentally retarded (ICF/MR) totalled $3.6 billion in FY 1982. Outlays for ICF/MR services are expected to climb to $4.2 billion in the current fiscal year. The federal share of such costs was $2.0 in FY 1982 and will approach $2.4 billion during FY 1984. This makes ICF/MR reimbursements by far the single largest source of federal aid to the states for services to mentally retarded persons.

II. Recent Trends

Since the late 1960's the states have emphasized the development of community-based alternatives to large, multi-purpose institutions. As a consequence, we have witnessed a steady decline in the number of persons residing in public and private institutions for the mentally retarded. For example, since 1967, when the population of public institutions peaked, the aggregate number of mentally retarded residents has declined by almost 77,000--or to 117,850 by June 30, 1982.

Meanwhile, there has been a sharp increase in the number and types of community residential and daytime programs for mentally retarded and other developmentally disabled persons. A 1977 survey, conducted by the University of Minnesota Center for Residential and Community Services, found that over half of the 4,427 community residential facilities serving the mentally retarded, nationwide, had been established within the preceeding five years. A more recent study by the Center revealed that the number of small community residences (serving 10 or fewer persons) almost quadrupled between 1977 and 1982 and the number of residents living in such facilities more than tripled (from 17,635 to 51,132).

The Commonwealth of Pennsylvania illustrates the historic changes which are taking place in professional and societal views of the most appropriate methods of serving mentally retarded persons. In 1966, Pennsylvania operated nine state schools for the mentally retarded serving a total of 13,470 residents. Today, the number of residents in Commonwealth institutions has declined to 6,400, or less than half the number seventeen years ago. Over the past 24 months, we have closed three state-operated mental retardation units and the Secretary of Public Welfare recently announced plans to phase out one of Pennsylvania's largest and best known retardation treatment facilities, Pennhurst State Center, by June 30, 1986.

Meanwhile, support for community-based living and programming alternatives has grown rapidly in Pennsylvania. The FY 1984-85 budget, which Governor Thornburgh submitted to the Legislature two weeks ago, requests $270.8 million for community mental retardation services, or 122.5 percent more than the amount expended just five years ago. In FY 1984-85, the Pennsylvania Office of Mental Retardation will serve:

- 6,792 clients in community residences, most of whom will live in small, home-like environments;
- 9,986 in sheltered workshops, work activity centers and other daytime habilitation programs;
- 6,363 in infant stimulation and other early intervention programs; and
- 14,181 mentally retarded persons and their families through various types of in-home training, respite and related assistance programs.

The trend toward serving mentally retarded and other developmentally disabled persons in the community is clear--not only in Pennsylvania but across the Nation. NASMRPD supports this trend. In our view, the fundamental question before this Subcommittee today is not the direction which future policy should take, but rather the manner in which federal law should be altered to facilitate this process, without jeopardizing the quality and appropriateness of services rendered to existing or future retarded clients.

III. Basic Assumptions

Before examining some of the practical problems inherent in S. 2053, as currently drafted, I want to underscore the fact that NASMRPD agrees with several of the basic premises that underlie the "Community and Family Living Amendments of 1983". For example, the Association agrees that:

- Existing federal Medicaid policy offers the states powerful incentives to place and maintain disabled persons in large, multi-purpose long term care institutions, since reimbursement for home and community-based service alternatives is not generally authorized under current law.
- Thousands of mentally retarded and other developmentally disabled persons who currently reside in public and private institutions would benefit from transfer to less-restrictive, community-based care settings.

- A fundamental goal of state residential systems serving mentally retarded and other developmentally disabled persons should be to assure that each client is placed in the most normalizing, least restrictive living environment, given his or her service needs.

- Steps need to be taken to build upon the precedents established under the Medicaid home and community care waiver authority if the states are to meet current and future demand for appropriate community living and programming opportunities.

IV. Commentary on S. 2053

While NASMRPD agrees with several of the basic premises of the "Community and Family Living Amendments", we also believe that were the bill to be enacted into law in its present form states would face enormous problems in implementing its provisions; as a consequence, many of the objectives which are being sought would not be realized. I would like to briefly review several key provisions of S. 2053 and outline the reasons why our Association feels they are ill-advised.*

A. Phasing Out Support for Larger Medicaid-Certified Institutions. Under the provisions of S. 2053, states would be allowed up to ten years to phase out Title XIX support for any Medicaid-certified long term care institution serving the severely disabled which did not qualify as a "community or family living facility", as defined in the proposed Section 1918(h)(2), provided the state had an implementation agreement with HHS that complied with Section 1918(i) of the bill. There are a number of practical reasons why many states would have great difficulty in fulfilling such a mandate, including:

- *States face significantly different problems as they attempt to accommodate their existing MR/DD service systems to the demands of the future and consequently, it would be nearly impossible to fashion an institutional phase-out schedule which would properly account for all of the unique social, demographic and political factors likely to influence policies in each state.*

- *Many states would be required to absorb the unamortized portion of the cost of institutional renovation projects mandated under past federal ICF/MR regulations.*

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* A more detailed discussion of the Association's views regarding S. 2053 is available by writing NASMRPD, 113 Oronoco Street, Alexandria, Virginia 22314.

- *The bill offers no assurances that federal funds will be available to support the contemplated expansion in community-based services.*

- *The quality of services in institutional facilities would be likely to deteriorate during the phase-out period.*

- *Objections from clients and parents to community placement would complicate the task of meeting the institutional phase-out schedule mandated under the bill.*

B. Developing Community Alternatives. As noted above, states would be required to enter into a "community and family implementation agreement" with HHS in order to qualify larger residential facilities for continued Medicaid support during the phase out period. The overall effect of this mandatory phase out provision of S. 2053, combined with the detailed stipulations of the implementation agreement, would be to shift responsibility for formulating Medicaid long term policy, as it affects severely disabled persons, from the states to the federal government. NASMRPD believes that such a shift would: (a) be incompatible with the basic philosophy of a federally assisted, state administered program such as Medicaid; (b) lead to significant inequities in implementation because of the previously mentioned differences in needs and resources among the fifty states; and (c) be difficult to implement because HHS lacks the specialized staff resources necessary to properly administer the program called for in the bill.

NASMRPD also is concerned that several of the obligations states would be required to undertake in order to maintain an acceptable implementation plan are unrealistic, including:

- *Federal training funds are not authorized under present or proposed law, even though S. 2053 would obligate the states to provide training services to community program staff.*

- *Lack of community acceptance would be a barrier to achieving the proposed institutional phase-out schedule in many states.*

- *The risk of developing substandard community programs would increase, if S. 2053 were enacted into law.*

- *Billions of dollars in capital outlays would be required to construct safe, accessible community residences for the multi-handicapped, non-ambulatory residents who remain in public and private institutions.*

- *The proposed employee protections do not solve the enormous logistical and political problems many states would face if they were required to phase out Medicaid support for all* *large public institutions according to the schedule set forth in the bill.*

- *The provision for parental appeals, contained in Section 1918(i)(1)(k) of S. 2053, would be difficult to administer and afford the states inadequate protections.*

- *The bill, as drafted, would place too much authority and control in the hands of providers of residential services.*

C. Eligibility for Services. In S. 2053, the term "severely disabled individual" is defined in the same manner as the term "developmental disability" in the Developmental Disabilities Assistance and Bill of Right Act, except that: (a) the age of onset of the disability would have to have occurred prior to age 50, rather than 22; and (b) mentally ill persons between the ages of 21 and 64 would be treated as ineligible for benefits.

Limiting benefits to persons disabled prior to age 50, in our view, makes little sense in the context of overall Medicaid policy. It is difficult to argue, for example, that a 45-year old bus driver who sustains a serious spinal cord injury in a traffic accident should be entitled to an entirely different set of benefits than a similarly injured colleague who happens to be 55 years old.

Furthermore, state and federal outlays for long term care services on behalf of severely disabled Medicaid recipients would rise percipitously if S. 2053 were enacted into law--primarily because of the additional number of clients who would become eligible for Title XIX reimbursable services. Based on an analysis of available data, NASMRPD calculates that *the number of retarded persons who would be eligible for long term care benefits under Medicaid would at least double in the short run and more than triple in the longer term.* And, these estimates do not even begin to account for the effect of adding thousands of non-retarded persons who would become eligible for long term care services under the bill; nor do they factor in the increased marginal costs of operating larger public and private institutions over the ten to fifteen year phase out period that would be authorized under the bill.

With the federal government struggling to keep the deficit under $200 billion annually and many states facing difficulty in sustaining current service levels despite recent tax increases, we feel it is essential that individuals and groups interested in the welfare of severely disabled individuals conceptualize an incremental strategy for altering Medicaid policies that: (a) is consistent with the goal of offering eligible severely disabled recipients long term care services appropriate to their needs in a setting which maximizes their opportunity for growth and self-fulfillment; and (b) assures reasonable, controlled growth in Medicaid outlays over the next five to ten years.

D. Covered Services. Under the provisions of S. 2053, a wide range of home and community-based services rendered to Title XIX-eligible, severely disabled persons would be treated as reimbursable costs under the Medicaid program. The way in which several of those services are defined deserves comment:

- Home or Community-Based Health Care Services. The bill indicates that such services as "...described in Section 1915(c)(4)(B)" of the Act would be reimbursable under the proposed program for severely disabled persons. The cited section of the Act outlines services that may be covered under an approved home and community care waiver program. However, the technical language of S. 2053 leaves some doubt in our mind as to whether the drafters intended to authorize Medicaid reimbursement for all, or just certain, services currently fundable under a Section 1915(c) waiver.

- Comprehensive Services for Independent Living. No one would deny that severely disabled persons can benefit from independent living services or that demand for such services greatly exceeds the current supply. The question is: should such services be reimbursable under the federal-state Medicaid program. Section 702(b) of the Rehabilitation Act of 1973, as amended, defines the term "comprehensive services for independent living" to mean "...any appropriate vocational rehabilitation service...and any other service that will enhance the ability of a handicapped individual to live independently and function within his family and community and, if appropriate, secure and maintain appropriate employment." Traditionally, vocational rehabilitation and job placement services have not been treated as reimbursable expenses under the Medicaid program.

- Room and Board. Since most potentially eligible recipients of benefits under the proposed new program for severely disabled persons would qualify for SSI benefits, we see no reason to treat room and board costs as a Medicaid reimbursable service. The notion of an individual entitlement to cash assistance, NASMRPD believes, is more compatible with the goal of fostering independence and self-reliance, which is the hallmark of community-based services. By contrast, the single vendor payment approach, which has long characterized Medicaid long term care policy, tends to reinforce the client's dependency on the provider of services.

E. Standards Applicable to Non-Complying Facilities. In order to avoid reductions in federal payments for administrative costs incurred in operating the Medicaid program, states would be required under S. 2053 to give assurances that periodic independent reviews of all large, former ICF/MR facilities would be conducted, to assure that they remained in compliance with federal ICF/MR standards. In other words, compliance with federal standards would be mandatory in decertified facilities. We doubt that such a provision would be upheld in court, if, as seems certain, it were to be challenged on either statutory or Constitutional grounds.

F. Enforcement and Penalty Provisions. The bill incorporates a confusing array of auditing and oversight requirements. NASMRPD members recognize the states' continuing obligation to maintain proper accountability for federal Medicaid funds. However, we believe that the present requirements of the Chafee bill would lead to duplication of effort and consequently impede effective implementation of the program.

Finally, S. 2053 would permit any interested party to file suit in federal district court if he or she felt the terms of the Act were being violated. NASMRPD fears that such an open-ended authority to litigate would lead inevitably to suits that would hinder, rather than advance, effective implementation of the program.

V. NASMRPD's Alternative Proposal

While our Association opposes the enactment of S. 2053 in its present form, we strongly support statutory modifications in Title XIX, aimed at encouraging the states to expand and improve community-based alternatives to large institutions. In this concluding section of my testimony, I will outline for the Subcommittee a coordinated set of statutory amendments which, NASMRPD believes, would reduce the "institutional bias" of present Medicaid policy, as it applies to the provision of long term care services to eligible developmentally disabled clients. The ideas expressed below are not intended to be a polished legislative proposal, but rather a preliminary attempt to identify a reasonable middle ground between those who are satisfied with existing Medicaid policies and those who believe that Title XIX support for all long term care facilities serving more than fifteen non-elderly disabled recipients should be phased out over the next 10 to 15 years.

With these thoughts in mind, NASMRPD recommends that the following changes be made in existing law:

A. *Optional Coverage. Add "home and community-based services", as that term is currently used in Section 1915(c)(4)(B) of the Social Security Act, as an additional service which states may elect to cover under their medical assistance plans, for recipients severely disabled since childhood, in accordance with the* *provisions of Section 223 of the Social Security Act, and otherwise requiring long term care in a Title XIX-certified institution.*

Under current law the Secretary of Health and Human Services may approve waiver requests submitted by states desirous of providing Medicaid-reimbursable home and community-based services to eligible recipients who, in the absence of such services, "would require the level of care provided in a skilled nursing facility or intermediate care facility..." (Section 1915(c)(1) of the Act). As of December, 1983, 31 states had submitted a total of 48 such requests to HHS which explicitly asked for authority to provide home and community care services for mentally retarded and other developmentally disabled recipients. Twenty-nine (29) of these requests had been approved, three (3) had been disapproved and one (1) withdrawn; final action was pending on the remainder.

Despite the advantages of the waiver program compared to past policies and the clear evidence of the states' willingness to use this alternative method of financing, there are several features of the current statutory and regulatory authority which suggest that, in the long run, it may prove to be an imperfect vehicle for encouraging states to utilize lower cost home and community-based care options. One prominent drawback of the waiver authority is that it offers a state little incentive to move systematically, over a period of years, to expand the number and types of community-based services available to eligible severely disabled recipients with long term care needs, thereby making it possible to reduce the number of such persons who are inappropriately placed in institutional settings.

Furthermore, from the point of view of a participating state, the waiver process represents a less secure method of financing services than those available under a regular state plan amendment. With a waiver, for example, the Secretary can withdraw approval just as simply as she initially approved the state's request.

Finally, despite the fact that there is no statutory expiration date for the home and community care waiver program, the legislation is generally viewed in Washington as an experimental attempt to test the hypothesis that long term care services for elderly and disabled persons can be provided more economically and humanely if the states are given greater freedom to choose among a wide array of Medicaid reimbursable service alternatives. Indeed, the very notion of a waiver authority is derived from the Secretary's long standing statutory power to grant waivers for the purpose of demonstrating new approaches to providing services and cash assistance to persons eligible for federally-assisted welfare benefits (Section 1115 of the Social Security Act).

Given the fact that many states with approved Section 1915(c) waiver programs have substantially realigned their methods of financing community-based services for developmentally disabled clients, the elimination of this authority, or major constraints on its future use, could be highly disruptive. Thus, continuity of federal support is a major concern of participating states, especially in view of the likelihood that most waiver-eligible program participants will be dependent on public support, in one form or another, for the remainder of their lives.

As an initial step toward addressing these drawbacks of the existing waiver program, the proposed legislation would amend Section 1905(a) of the Act by allowing states to offer home and community-based services for certain, high risk developmentally disabled recipients, as an optional coverage under their state Medicaid plans. Except as specified below, the range of services reimbursable under this proposed optional state plan element would be the same as those currently specified in Section 1915(c)(4)(B) of the Act (see discussion under Item D below). Eligibility for such services still would be restricted to clients who were either currently residing, or at-risk of placement, in Title XIX-certified long term care facilities.

We believe there are several sound reasons for drawing the parameters of eligibility in this manner. First, clinicians and program administrators generally agree that severe, prolonged disabilities occurring at birth or during a child's early development require significantly different treatment and life management strategies than disabilities of similar severity that occur after the individual reaches adulthood. Second, states are organized to deliver services to persons who meet the definition of eligibility suggested above; in contrast, existing service delivery responsibilities would have to be completely revamped, at tremendous expense in both dollars and time, if eligibility were to be extended to disabled persons up to age 50. And, finally, NASMRPD's proposed definition would assure that home and community services would be focussed on the appropriate target population--those most likely to be institutionalized or at-risk of institutionalization.

B. *Requirements of Participation. Amend Section 1915(c) of the Act to specify that, on or after July 1, 1985, in order to qualify for approval of a new or renewal waiver request on behalf of recipients with severe disabilities originating in childhood (as that term is defined in Section 223 of the Act), a state must agree to: (a) offer home and community care services for such recipients as an optional coverage under its state Medicaid plan, beginning no later than July 1, 1990; and (b) develop and implement a ten year plan aimed at minimizing the number of such recipients inappropriately placed in large institutional settings.*

Among the states specific obligations under this provision of the legislation would be to: (a) establish a comprehensive screening and assessment program to identify developmentally disabled persons inappropriately placed in skilled nursing, intermediate care and intermediate care facilities for the mentally retarded; (b) describe the level of care criteria, policies and procedures, it would use to determine whether a disabled applicant is qualified for admission to a SNF, ICF or ICF/MR facility (and, thereby, eligible to receive community care services) and, if so, whether he or she would benefit from such non-institutional services; (c) establish a pre-admission screening program aimed at preventing future inappropriate placements of developmentally disabled persons in SNF, ICF or ICF/MR-certified facilities; (d) outline a systematic plan to reduce the number of developmentally disabled persons inappropriately placed in institutional settings over a ten year period; (e) describe the steps that would be taken to develop the home and community care services required to meet the needs of persons inappropriately placed in Title XIX-certified long term care institutions, as well as to deflect future institutional placements; and, (f) describe the steps that would be taken to assure that the activities of responsible state and local agencies are properly coordinated to achieve the objectives described above. Any state which failed to fulfill its obligations under this agreement with HHS would be subject to fiscal sanctions.

There are several reasons why NASMRPD believes that the proposed extension of optional coverage for community care services on behalf of certain developmentally disabled recipients would be a prudent step. First, since eligibility would be restricted to persons severely disabled in childhood, who are either residing in Title XIX institutions or at-risk of placement in such facilities, the total number of recipients potentially eligible for community care benefits would be relatively small. Second, as is the case under the existing Section 1915(c) waiver authority, states would be obligated to demonstrate the cost effectiveness of community alternatives, compared to institutional costs, and, therefore, it should be possible to avoid uncontrolled growth in program outlays. And, finally, most states already have well-established networks of community care services for developmentally disabled persons upon which to build. Generally, community care systems for frail elderly and other disabled Medicaid recipients are not as well-developed.

C. *Increased Matching Ratio. Amend Section 1902(a) of the Act, effective July 1, 1985, to increase the federal matching ratio for home and community-based services, delivered in accordance with an approved Section 1915(c) waiver request or as an optional service under a state's Medicaid plan on behalf of certain developmentally disabled recipients, by five percentage points above the percentage a state is otherwise entitled to receive under the provisions of Section 1905(b) of the Act.*

The purpose of this amendment would be to give the states a positive fiscal incentive to develop community-based alternatives for developmentally disabled persons who are at-risk of institutionalization. It would entail some additional federal outlays, but since services would be restricted to persons currently institutionalized or at-risk of institutionalization in a Title XIX-certified facility, presumably the increase would be offset, at least in part, by the generally lower average per capita costs of home and community-based alternatives.

Unlike a similar provision in the Chafee bill, the proposed differential matching for home and community-based services would not be: (a) restricted to persons residing in Medicaid-certified institutions as of the date of enactment of the legislation; or (b) limited in duration to five years after an institutionalized recipient was placed into a community-based setting. Therefore, the states would not be faced with perverse fiscal incentives in attempting to establish service priorities. Nor, would they have to worry about "making up the difference" when the period of differential matching expired.

D. *Coverage of Pre-Vocational Services. Explicitly authorize the states to cover pre-vocational services for eligible, non-elderly disabled persons under a home and community care waiver program and/or a state plan amendment (as discussed under Item A above), provided certain conditions are met.*

Most states which have submitted waiver proposals aimed in whole or in part at providing home and community-based services to eligible developmentally disabled persons are offering, or intend to offer, day habilitation services which include task-oriented activities intended to help participating clients to acquire the social and job-related skills that are prerequisites to entry into a vocational training program. Generally, such clients are capable of very limited productivity, but they nonetheless need the opportunity to engage in such training programs if they are to make a successful and permanent adjustment to living in the community.

HHS attorneys have prepared an informal opinion indicating that neither vocational nor pre-vocational training services should be considered reimbursable expenditures under a home and community care waiver. In view of the indistinguishable line between work-related training and other habilitative activities in the case of such clients, a growing number of states have been expressing concern that they may be subject to sizable disallowance, unless existing federal policies are clarified.

The proposed amendments would modify Section 1915(c)(4)(B) of the Act by adding the following parenthetic qualifier after the words "habilitation services": "(including pre-vocational services for any eligible non-elderly client who is disabled as defined in Section 223 of the Act and is participating in a program certified as a "work activities center" under the provisions of Section 14(c) of the Fair Labor Standards Act)". In other words, to qualify as a "habilitation service" under a waiver, or the state plan amendment proposed above, prevocational activities would have to be provided to clients who were determined, in accordance with the basic Social Security Act definition of disability, to be "...incapable of engaging in substantial gainful activity"; also they would have to be receiving such services in a program certified by the U.S. Department of Labor as serving individuals whose work productivity is "inconsequential."

E. *Limitations on the Secretary's Authority to Approve Waivers. Amend Section 1915(c)(2)(D) of the Social Security Act to limit the Secretary's authority to place certain restrictions on the manner in which average per capita expenditures are calculated for purposes of determining: (1) whether a state qualifies for a home and community care waiver; and/or (2) is eligible to furnish such services under the proposed optional state plan amendment discussed above.*

At the present time, HHS officials use a regulatory formula to determine whether a state's waiver request meets the statutory test of having projected average per capita expenditures *with* the waiver that do not exceed average per capita expenditures *without* the waiver. Furthermore, in reviewing state waiver requests, the Department looks specifically at a state's comparative utilization estimates. Generally, requests which project a significant growth in the number of persons eligible for Medicaid reimbursable long term care services with vs. without the waiver program are not approved. The net effect is to severely limit the utility of the waiver program as a mechanism for developing community-based services on behalf of elderly and disabled persons who are "at-risk" of institutionalization in a Title XIX-certified facility.

The proposed amendments would have the effect of mandating administrative policies that carry out the original intent of Congress in including Section 1915(c)(2)(i) in the Act. It would accomplish this end by limiting the Secretary's authority to issue regulations or other administrative policies circumventing this intent.

V. CONCLUSION

In summary, the major aim of the proposals discussed above is to build incrementally on the existing home and community care waiver authority. NASMRPD wishes to make clear that these proposals are not intended to offer a solution to all of the complex problems of assuring appropriate care for severely disabled persons with chronic health, social and developmental needs. Instead, they are an attempt to outline a coordinated set of statutory changes that may be achievable over the next few years.

Inherent in the legislative changes NASMRPD is proposing is a recognition that: (a) society's view of the number and types of developmentally disabled persons who can be served more appropriately in community-based programs is changing and, therefore, federal policy should allow the states the flexibility to accommodate to these changes; (b) individual decisions regarding the appropriateness of community care cannot be divorced from the availability of resources to meet a given client's needs, at any point in time, if we are committed to assuring that developmentally disabled persons receive services in the community that are of equal or higher quality than those provided in large institutional settings; (c) size of a client's living environment should be just one of many factors used to determine the appropriateness of any client's residential placement; and, (d) states are at varying stages of implementing community-based service systems for developmentally disabled persons and, consequently, federal Medicaid policy should encourage each state to design its own strategies for expanding and improving such services, rather than assuming that all states can and should meet a uniform national schedule for phasing out large institutional facilities.

As the Association's spokesperson, I want the members of this Subcommittee to know that the leadership of NASMRPD is committed to the enactment of legislation that will improve the quality, appropriateness and accessibility of services for mentally retarded and other developmentally disabled citizens. In pursuit of this goal, we stand ready to work closely with the members of your staff and other individuals and organizations who share similar objectives.

Thank you for this opportunity to share our Association's views. If we can be of further help, I hope you will call on us.

Senator **Chafee**. It seems to me that one of the major points of opposition, from this witness and many others, is going to be that we are taking away an alternative. In other words, if you mandate the community-based setting, then you are—as Dr. Howse said—not leaving the institutional, if we can use that word, setting, and the indication is that some patients might do better in the institutional setting than they would in the community-based one; or, as Senator Exon said, in some cases bigger could be better.

I think we want to address that, particularly in thinking of what Dr. Braddock said. As the numbers in the institution shrink in size, the cost of the per-patient per-day care in the institution rises very, very dramatically. If you have an institution for 1,500, the expenses are so much; but if the population of that institution becomes 300, you are left with many of your fixed costs, fixed operating costs, and so the per-patient per-day expenses are extremely high. I think we have to consider that. I will be interested in what the witnesses have to say.

I will turn it back to you, Mr. Chairman. Glad you're back.

Senator **Durenberger**. All right.

Senator Bloom.

STATEMENT OF HON. PRESCOTT E. BLOOM, STATE SENATOR, STATE OF ILLINOIS GENERAL ASSEMBLY, ON BEHALF OF THE NATIONAL CONFERENCE OF STATE LEGISLATORS

Senator **Bloom**. Thank you, Mr. Chairman. It's kind of unusual being on this side of the table.

This past December I became chairman of the National Conference of State Legislatures' Special Committee on Health Care Cost Containment. I am here to represent the NCSL.

Our policy is that we believe that appropriate alternatives to institutionalization which are effective in maintaining the population in their communities at a cost below institutional care should be encouraged as a part of any comprehensive Federal long-term care policy.

We basically are: "Aye" on the concept of S. 2053 but "No" on the bill right now as it is presently written. It appears to be a little more stick than carrot.

Speaking as someone from central Illinois—my district cuts across two congressional districts; I am Peoria-based—I see our Illinois Association for Retarded Citizens profoundly split on this issue—profoundly, and deeply, and emotionally split.

I would like to pick up on the capital issues. To a degree in the 1970's, the mid-1970's or late-1970's, the States were trying to bring their State institutions up to Federal standards and to get accredited through medicaid, and so on and so forth. Our concern is that a State can't be a size 10 to size 16 shoe; they have different requirements, and we need the flexibility. And our own Department of Health didn't get their medicaid waivers until fiscal year 1983.

In my own district, we are closing Galesburg Mental Health Center, a very, very traumatic experience for many of the parents. If this bill were law tomorrow, then one of the alternatives that presently exist, St. Mary's on the Square, would not be allowed.

St. Mary's on the Square was an outmoded hospital. Folks didn't know what to do with it. Some people bought it and turned it into apartment-living for the developmentally disabled, and these men and women work in the Galesburg Community Workshop area and are functioning parts of society. That should be encouraged. But it is an apartment complex of almost 100 people.

Another point, we are concerned with. This bill does not address the dual diagnosis problem. I had the misfortune of inspecting Galesburg Mental Health Center three times because of the closure. Galesburg is just one of four mental health centers that have been closed in the last 18 months in Illinois. Pointing toward community-based care, and I know the pressures that are being put on the community-based care system.

There is a segment of the developmentally disabled or the retarded population, profoundly retarded, heartbreaking situations where people need 24-hour-a-day care, and you have to leave us a little more flexibility to address these situations than S. 2053 presently does.

I will answer any questions you have. We have submitted our full statement.

Thank you.

Senator **Durenberger**. Thank you very much.

Dr. Carl.

[Senator Bloom's prepared statement follows:]

"THE COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983"

S.2053

by

THE NATIONAL CONFERENCE OF STATE LEGISLATURES

Represented by:

SENATOR PRESCOTT E. BLOOM, ILLINOIS

Before the:

SENATE FINANCE SUBCOMMITTEE ON HEALTH

February 27, 1984

STATEMENT OF SENATOR PRESCOTT BLOOM ON S.2053

Mr. Chairman and distinguished members of the committee, it is indeed a pleasure to appear before you today to present testimony on behalf of the National Conference of State Legislatures (NCSL*) on S.2053, the Community and Family Living Amendments of 1983. I am Prescott Bloom from Illinois, where I serve in the state senate. I also serve as the Chairman of the recently established NCSL Special Committee on Health Care Cost Containment, which is an issue of great interest and concern to me, personally, and to my state. The special committee will meet over the next several months to discuss and review a number of state and federal cost containment initiatives.

The NCSL Human Resources Committee which is responsible for guiding the Conference policy on health, income maintenance, and social services, has not had an opportunity to consider specific policy on S.2053. We believe that NCSL long term care policy is applicable. The NCSL policy states in part:

> "A comprehensive federal long term care policy which addresses the health and social needs of the frail elderly population and the physically and the mentally disabled should be developed and state involvement in the formulation of such a policy is crucial. Federal legislation should be patterned on successful program innovations which have been developed and tested at the state level. The National Conference of State Legislatures believes that appropriate alternatives to institutionalization which are effective in maintaining this population in their communities at a cost below institutional care should be encouraged as part of any comprehensive federal long-term care policy. Alternative programs may be a cost efficient means of reducing costs and, in addition, promote a better quality of life for our frail elderly and disabled people..."

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* The National Conference of State Legislatures (NCSL) is the official representative of the country's 7,438 state lawmakers and their staffs. It is the only national legislative organization governed and funded by the states.

NCSL would rather see the development of a comprehensive federal policy which addresses all of the problems and concerns states have in the delivery of long term care services regardless of the population receiving them.

The problem of economically and effectively providing health care service for populations in need of long term care is an area of major concern to the states and will be part of the focus of the NCSL Special Committee. This is a complex and difficult issue that Illinois and a number of other states are dealing with. A recent NCSL survey of the states found that 51 bills relating to nursing homes and alternatives to institutional long term care will be introduced in state legislatures during the 1984 legislative session. States are cautiously seeking Medicaid waivers to provide a range of home health and community based health services to avoid premature and unnecessary institutionalization. These community care waivers authorized under Omnibus Budget Reconciliation Act of 1981, (OMBRA), have been extremely popular in the states. As of November of last year, the Health Care Financing Administration (HCFA) had received 46 state applications for 100 waivers.

Over the last 20 years, the movement at both the state and federal levels has been to change service delivery pratices to accept the principal of "normalization" and to provide care in the least restrictive setting to enhance the individual's habilitation. States are moving towards the deinstitutionalization of the elderly, and the mentally and physically disabled. Some states have moved rapidly to accomplish this goal, while others have proceeded more cautiously.

Senator Chafee's bill addresses a subgroup of the long term care population, the severely mentally retarded and disabled who are medicaid eligible. Under the proposal, such persons would be eligible for Medicaid assistance only if they were living in a family home or community based facility, as defined in the bill. I commend Senator Chafee for meeting the challenge and taking the initiative to develop a proposal in this important area; however, the bill raises a number of questions and potential problems for the states which we feel must be addressed.

The problems associated with the provision of long term care services are broad, far reaching and not limited to the elderly, the mentally retarded, the physically disabled, or any subgroup of these, but, encompasses them all. Many of the support services necessary for the care of one group is equally necessary for the others, consequently a comprehensive approach to the provision of long term care may be indicated. The states are well aware of the differences between the populations served, in particular, the increased service demands of the severely disabled versus those of the frail elderly needing long term care. Elderly patients typically require more intensive services at the end of their lives, while the severely disabled require an array of services across an entire life span. Services for the handicapped, however, are usually oriented toward skill acquisition and independence rather than medical or respite services provided to the elderly. For the disabled the need for services may decrease over time as they acquire independent living skills. However, certain basic services such as housing, primary health services and nutrition services are needed across the board. Here, as well as in other areas, states believe there is potential for developing a more cost-efficient way of delivering those services.

Again a comprehensive national policy which involves the states experiences on needs in long term care would help resolve many of the conflicts states presently operate programs under. We believe that the analysis of the needs of the long term care population overall and the targeting of needed services to those individuals who need them, in whatever setting, be it community based or within an institution, is the critical concern.

Over the years, the states have made a considerable financial commitment to rehabilitate, modernize older facilities, or to construct new facilities. Much of this work would be lost under the provisions of S.2053, as many of these facilities would not qualify under the bill. This is an area of great concern to state legislatures, particularly those that have recently allocated funds to construct or modernize state facilities in order to meet compliance standards to receive reimbursement under Medicare and Medicaid. It is estimated that the capital commitment over this 20 year period has been in excess of $1 billion.

NCSL is extremely supportive of the community care waivers available under the Medicaid program. We believe the increased experimentation should be encouraged under this existing provision to help states continue the movement toward community based care where it is determined such care is desirable and cost effective. The Community and Family Living Amendments Act of 1983 should provide an impetus to expand the existing authority under the Medicaid program to further study the special problems associated with the provision of long term care to the severely mentally retarded in the context of a comprehensive long term care policy.

Finally, the states must have adequate funding and flexibility to develop the expanded support service network which will be needed to allow families or community based programs to care for the severely mentally retarded or disabled. Although it may be assumed that the benefits of family and community based programs will lessen an individual's reliance upon institutional services, a more complete array of support services will be needed to maintain individuals in their communities. Adequate federal funding will be needed to design and maintain that array of services. States should also have program flexibility to provide those services they know are needed to adeuqately support individuals on a local level.

I thank you for this opportunity to share the views of NCSL with this distinguished panel. NCSL looks forward to working with you on the development of a comprehensive long term care strategy to assist all those in need of these services.

STATEMENT OF ROBERT L. CARL, JR., PH. D., ASSOCIATE DIRECTOR, DEPARTMENT OF MENTAL HEALTH, RETARDATION AND HOSPITALS, DIVISION OF RETARDATION, STATE OF RHODE ISLAND

Dr. **Carl**. Thank you, Mr. Chairman, and members of the committee.

You have the statement that Mr. Gunther and I submitted jointly from the State of Rhode Island. I am one of those other 49 State directors that Dr. Howse references, and I'm here to support S. 2053.

I am here to support S. 2053 because basically it is what makes sense and it is what's right on behalf of the people who are unable, by and large, to speak for themselves.

Nobody would design the kinds of living that these people have been put through and that they go through today, those people who are institutionalized. No one would willfully and purposely design that kind of a living arrangement.

I have traveled throughout these United States, I have operated State institutions in several States, and I continue to travel. In the last several weeks I have visited public institutions in several other States in America. There are places that you would not let your dog stay in. There are places that are a shame for this country.

What makes it a particularly shameful experience is that we are pouring billions of dollars into shoddy care, and we are doing that under the guise and under the pretension that these people need these kinds of services, when as a matter of fact all practical evidence is that these folks, like all the rest of us, do best when they are treated like folks—in small settings—where they are treated with dignity and treated with individuality. They are not lumps of protoplasm; they are not just retarded folks; they are people, first.

When these people are treated as individuals—and come to Rhode Island; I can show you the most severely retarded and the most profoundly retarded and the most multiply handicapped people living in community settings, living well in community settings, small four-person homes and six-person homes and two-person apartments, thriving, growing, living, and proud of themselves—they may not be able to talk, or they may talk a little bit funny; they might not walk very well; they might have a whole host of problems, and they may not be going to Harvard; but they are people, and they will thrive when they are treated as people.

They will not do well when they are not treated as people; that's what we've done in this country, that's what the medicaid program today encourages in most State institutions, it is to keep people in bad places, inappropriate places.

Thank you, Senator

Senator **Durenberger**. Thank you very much, Doctor.

George Gunther.

STATEMENT OF GEORGE W. GUNTHER, JR., CHIEF ADMINISTRATIVE OFFICER, DEPARTMENT OF MENTAL HEALTH, RETARDATION, AND HOSPITALS, DR. JOSEPH H. LADD SCHOOL, STATE OF RHODE ISLAND

Mr. GUNTHER. Mr. Chairman, I am the superintendent of an institution for the mentally retarded in Rhode Island which has 397 people living there. In addition to that, I am also the operator of a community program throughout the State of Rhode Island which operates group homes and apartments throughout the State for four to six persons in the group homes and two people in the apartment programs, so about 125 people.

I am also the parent of a 25-year-old retarded woman who lives in the institution. So from that background, this is what I have to say:

Over the last decade in the United States, over 50,000 persons have left institutions and returned to the community. There now remains about 115,000 persons in public institutions for the retarded. This legislation addresses the 115,000 persons in addition to preventing thousands of others from entering institutions in the future.

This legislation encourages the development of a community-based residential and day-service system to replace the institution. And looking at the United States on a State-by-State basis, the community-based resident and day-service system either does not exist in some States or it exists in a portion of the State, or it is an incomplete system in many States where it does exist.

Over the last decade, since the beginning of the ICF/MR program, States have been encouraged to and indeed have made huge financial investments in institutions, both in improvements to the physical plant and increases in the staff.

The professional groups and persons who oppose this legislation raise some legitimate technical concerns about the elements of the legislation, but the primary thrust of the bill is accurate and basically raises a major policy issue for the U.S. Federal Government, which is: Should the Federal Government continue to invest huge sums of money in a system of care such as large multipurpose institutions when all of the evidence and professional body of knowledge recognizes this as a system that has outlived its usefulness to the citizens who are retarded in the United States?

If one were to posit the answer as no, we should not continue to invest this money in this kind of a system, then one needs to address the elements of a bill that can effect the development of a proper community-based system with a corresponding reduction of institutional services in an orderly manner.

S. 2053 sets the stage for this to occur. The testimony we have submitted suggests assurances that various groups need to support this excellent concept as I do.

Thank you.

[The prepared statement, joint, of Dr. Carl and Mr. Gunther follows:]

Testimony to the United States Senate Committee on Finance Re: S2053

February 27, 1984

Room SD-215
Dirksen Senate Office Building
Washington, D.C.

Filed with:

Roderick A. DeArment, Esquire
Chief Counsel
Committee on Finance

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and

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George W. Gunther, Jr.'s Background:

In the twenty-five years that Mr. Gunther has been in the field of retardation, he has had the opportunity to review services from a variety of perspectives. First, he is the parent of a twenty-five year old woman who is retarded, and resides at the Dr. Joseph H. Ladd Center of which he is the Chief Administrative Officer. He is a past Board Member of the National Association of Retarded Citizens, and a past Board Member of the American Association on Mental Deficiency.

Dr. Robert L. Carl, Jr.'s Background:

During his fifteen year professional career, Dr. Carl has both, directly administered institutional settings in Massachusetts and Ohio, and been responsible for the development of various community services in Rhode Island. He has served as a consultant to the United States Department of Justice, numerous state and private agencies, and to various professional and parent-consumer groups.

In the 1850's, Dr. Samuel Gridley Howe established the first public institution for retarded citizens in this country. Within ten years, Dr. Howe had publicly decried this action, and called for the closure of this facility. He correctly predicted the inhumanity and inappropriateness of institutional care which has faced our retarded children and friends for this past century and a quarter.

Although President John F. Kennedy promoted new national policies in the 1960's to improve our nation's capacity to care for our least fortunate citizenry, 1965 saw the publication of a book* in graphic pictorial format which documented our inhumanity to institutionalized retarded citizens. When Bengt Nirje, Director of Sweden's organization of parents of retarded children, visited the United States in 1969, he compared the many public institutions housing retarded persons with Nazi Germany's concentration camps.

In 1973, the Federal Government made a major commitment to instititional care for retarded citizens through the Medicaid program. From this date forward, Federal funding has been available to all states for certain institutional and other services. During the past decade, hundreds of millions of Federal dollars have been spent in these state institutions. From 1973 to 1983, we also saw a population reduction in public institutions for retarded citizens by more than 50,000 persons. At this time, fewer than 115,000 persons remain in these public facilities. This population reduction has been the direct result of dozens of Federal law suits, as well as more enlightened state legislation in response to Federal Court decisions.

For years, most professionals in the retardation field have agreed in favor of community care for persons with retardation. Most of us have preached the dual messages of more humane care and lower per person expenditures. Yet many people and most organizations involved in retardation services are apparently terribly threatened by the mere submission of a piece of legislation (S2053) designed to promote community services for retarded citizens, and halt the expenditure of millions of dollars on clearly scandalous institutional care nationwide. In state after state, media exposes Federal and State law suits, advocacy groups complaints all document regularly and publicly the shame of these institutional services. Even the present United States Department of Justice avowedly non-interventionist and non-litigational in posture, has documented the disgrace of public institutional services for retarded citizens in state after state throughout the country.

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*Blatt, Burton, Christmas in Purgatory, Longman, Inc., New York New York, 1965

We wonder what the opponents of S2053 fear? Surely, they cannot favor the past or present conditions? We propose that the following be considered.

The Community Living Amendments Act appears to be a progressive piece of legislation supported by the National Association of Retarded Citizens. If this is so, why is it that Senators and Congressmen have received so much mail against the proposed legislation?

It is the intention of this testimony to avoid a line by line review of the proposed legislation and technical aspects and to address the broader implications as we see it.

Over the last decade in the United States, over some 50,000 persons have left institutions and returned to the community. There now remains about 115,000 persons in institutions for the retarded. This legislation addresses the 115,000 persons in addition to preventing thousands of others from entering institutions in the future.

This legislation encourages the development of a community based residential and day service system to replace the institution. In looking at the United States on a state by state basis, the community based resident and day service system, either does not exist in some states, or exists in a portion of the states, or is an incomplete system in many states where it does exist.

Over the last decade (since the beginning of the ICF-MR program) states have been encouraged to, and indeed have made huge financial investments in institutions, both in improvements to the physical plant and increases in the staff.

The professional groups and persons who are apposed to this legislation, raise some legitimate technical concerns about the element of the legislation, but the primary thrust of the bill is accurate and basically raises a major policy issue for the United States Federal Government, such as, should the Federal Government continue to invest huge sums of money in a system of care - such as large multi-purpose institutions - when all the evidence and professional body of knowledge recognizes this as a system that has outlived its' usefulness to the citizens who are retarded in the United States?

If one were to posit the answer as NO, we should not continue to invest this money in this kind of a system, then one needs to address the elements of a bill that can effect the development of a proper community based system with the corresponding reduction of institutional services in an orderly manner.

The elements need to address these broad concerns:

Retarded Citizens - They need a safe, properly supervised home with sufficient treatment services and a "home" atmosphere, such as a four to six person home for most, but not all. Serving retarded persons is not a geographic issue where one part of a state or country can serve and the other part cannot. Any service that can be delivered in an institution can be delivered in any neighborhood in America.

Parents and Family - They need assurance that a proper home will exist and be properly supervised and a system of services are in place before you can expect them to embrace an unknown program. Emphasis should be placed on moving as many clients as possible to community settings as fast as possible in an orderly manner, rather than emphasizing the closing of anything. If the openings are successful, the closings will simply follow.

Institution Based Professionals - As previously mentioned, professionals who work in institutions have participated in helping to move over 50,000 persons into the community. The chorus of concerns that is being raised by these groups require assurances that the community system will have the capacity and willingness to serve medically complex persons, medically fragile older persons, and retarded persons who exhibit some behavior problems.

Community Based Professionls - Just as the institution based professionals assisted in placing 50,000 retarded persons in the community, community based professionals participate in providing services to these persons who are now living in the community. Most of the clients, relatively speaking, have been the most capable clients in the institution. With less capable clients now entering the community, they need assurances that staff training and specialized support services will be available to sus-cain the retarded persons in the community. They also need assurances that the over ninety percent who already live in our neighborhood will not have services reduced as a result of the expanded services for formerly institutionalized persons.

Governor's Offices and Legislatures - Tremendous support from Governors and Legislatures throughout the country has resulted in huge investments of money in these institutions to bring them to the Federally mandated ICF-MR standards which improves the services and insures the continuation of over fifty percent federal reimbursement.

These groups need assurance that some relief would be available to assist the states in the payback of the bonds if these facilities were no longer used. In addition, assistance needs to be provided to states to develop reutilization plans for the institutions which generally have huge real estate value.

Community Acceptance - Assurances need to be provided to the community - at - large to insure all persons that retarded persons will be assimilated in communities to avoid having too many retarded persons living in one location. Proper supervision needs to be assured to alleviate fears of "dumping" persons in their neighborhood.

Unions - To the extent possible, discussions need to be encouraged that could result in re-training the experienced institutional staff to work in the new community based locations.

In conclusion, the basic elements of S2053 are far reaching, long overdue, and correct. To our knowledge, the major organizations involved, support the basic concepts of the Bill, but need assurances, such as, we have previously described in this document.

In support of these contentions, we briefly discussed below some of our experiences in our home state.

In Rhode Island, we have seen a steady, planful decline in the institutional population and a concurrent increase in community services. In 1970, there were 1,260 persons living at the Ladd Center, our single state retardation institution. Today, fewer than 400 persons still live at the Ladd Center. Future developments, now in progress, call for further population reductions to fewer than 200 persons by 1985.

Since 1979, over eighty small community residences for four to six retarded persons have been established in Rhode Island. During this same time, over two hundred new apartment settings have been established. Today, more than eight hundred retarded citizens live in fully or partially assisted community residences About 2,000 retarded adults attend various developmental or vocational day service programs throughout the state. A statewide Early Intervention Program services over 300 disabled infants and their families. Respite care services, genetic counselling, family subsidy payments to keep retarded persons at home, social services, behavioral training, and specialized health and dental services are all available throughout our state.

Much progress has been made, more remains to be accomplished. Primarily, however, our experience in Rhode Island shows that a combination of responsiveness from the Governor and General Assembly, strong advocacy from parents and friends, reasonable planning, and implementation strategies and a generous and caring public, can provide decent, dignified, and cost-effective services for our retarded citizens. We can settle for nothing less.

S2053 or some reasonable facsimile, will promote these kinds of community based services nationwide.

Senator **Durenberger**. Thank you very much.

To reiterate, the statements of all of the witnesses will be made a part of the record.

Chairman Dole, do you have a statement or comment that you would like to make?

Senator **Dole**. No. I just have a statement I will ask be placed in the record.

I appreciate the fact that these hearings are being held. I know this is very controversial. I was just checking the mail we have received in the committee plus mail I have received from my State. I still think it is worth careful consideration.

Generally in this committee we can work out some of the problems, and I hope we can do that based on the testimony we will hear today.

Senator **Durenberger**. Thank you.

Jack Danforth, do you have an opening statement?

Senator **Danforth**. No, thank you, Mr. Chairman.

Senator **Durenberger**. John.

Senator **Chafee**. Let me ask Mr. Gunther or anybody on the panel if they can answer this question. I am correct, I believe, in the statement that, as you reduce the population of an institution built for large numbers of patients, your per-patient per-day costs rise very, very dramatically. Is that a fair statement, Mr. Gunther?

Mr. **Gunther**. The fixed costs for the most part are not able to be reduced; however, 70 percent of the costs of an institution revolve around the staffing. So as you reduce the population, if you move the staffing and reduce it in some way, either by moving them with the client or through attrition or whatever other way, you are going to reduce the cost 70 percent.

Your basic fixed costs, however, for many items will remain, and costs will increase slightly

Dr. **Howse**. We have a slightly different picture in Pennsylvania. We are closing Pennhurst Center which is a very notorious facility for the mentally retarded. We are doing it through the medicaid waiver that was spoken about earlier, and the way we are keeping the per diem constant and not seeing a great increase is by reducing staff rather dramatically at the end of the previous fiscal year for which we intend to move people out. So, in other words, if you reduce your staffing costs—and in Pennsylvania our staffing costs are about 85 percent of the budget—if you reduce staffing costs prior to the movement of people out of the facility, you can keep your per diems a constant, and indeed drop your per diems.

Senator **Chafee**. I am surprised at that, because I would think you would have to have *x* number of people in your fire department, *x* number of people in your sewage plant, or whatever it is, as long as you have a big institution, whether there are 200 there or 1000.

But now, let me ask Dr. Carl this question: You have come out quite forcefully for this legislation, but what do you say about those who suggest that there should be a different setting for different people and that for some the community setting is not the the answer, for some the answer is an institution, and it doesn't have to be a horrible institution but it could be a good institution with, say, 200 people in it?

Dr. **Carl**. Well, all we have to do is find some of those really good ones, Senator. If we travel around the country, we won't find very many good ones.

It seems to me that the important thing, as we look at the institutions, is that we will find that they are (*a*) very, very expensive, and (*b*) very, very impersonal.

It seems to me that we will not find very many people who will opt as their first choice—I am not talking about parents and I'm not talking about professionals; I'm talking about the people who live there. I would suggest that very few of us professionals or parents would trade places with those people in even those good institutions.

It seems to me that those places, the big places, are not places anyone would opt for, anyone would select out as their first choice.

I am in favor of appropriateness of care. I am in favor of providing the adequate level of support and assistance that people need. Some people need lots of assistance; some people need a tremendous amount of support. And I think we can give them that.

However, the requisites for that kind of support are not geographically based. You can provide the same support in your neighborhood and my neighborhood or in an institution.

The real issue is: What is our commitment to personalized care and to individualized care? If we really care about what is best for individuals, then we will treat people as individual citizens.

Senator **Chafee**. OK, fine. Thank you very much.

Thank you, Mr. Chairman.

Senator **Durenberger**. Let me ask all of you one question that relates to the last statement, I think, that Dr. Carl made about how do we guarantee this quality of care.

What role does Federal money currently play in what some professionals call "case management"? In other words, outside of the money that is going to providers to provide services, how much of, what kind of, and from what source is money being spent with the individual, to make sure that that individual is getting the right kind of care in the most appropriate setting?

I sat here and listened to the reaction of Dr. Carl's statement and, because I have been in some of those institutions, I resent the implication that he laid across this country that every institution larger than whatever he knows in Rhode Island is only fit for dogs. [Applause.]

But I have to reach past what he knows that works and what other people may think works and ask myself if there isn't in place in a lot of communities in this country some mechanism—if you will a human mechanism—outside of the provider organization that assures me as a parent or assures the individual involved, or me as a tax provider, that there is quality of care. How do we know people are in the right setting, getting the right kind of care? What are we spending the title XX money on, for example? What are we doing at the county level by way of managing the services being provided to these people?

Dr. **Howse**. Senator, there is substantial difference between States in the methods by which quality assurance is accomplished. In the medicaid program it is a shared responsibility between Federal and States. There are Federal standards for quality of care that accompany Federal dollars, and States and the Federal Government share a responsibility to assure that those standards are being met.

Title XX is indeed another source that can allow for the reimbursement of case-management services; but, apart from that, what you will find in most States as the common ingredients of a quality-assurance system both for State centers, State institutions, and for community services are an individual habilitation plan that is monitored by a case manager, and you will also find external licensing or certification responsibilities that are carried out in connection with quality assurance.

Senator DURENBERGER. Maybe someone else can also respond to that, but do we find an inadequate financial commitment to that quality assurance program? I mean, there are places in my State where, yes, the plan is in effect and it looks good if you go and look at somebody's file, but when is the last time anybody actually went out there to an institution and confirmed whether or not that plan for that particular person was being implemented?

Senator BLOOM. In Illinois, outside of the turf wars that sometimes crop up between public health and mental health, the Peoria area retarded citizens and the various independent living programs they run, they go through hands-on inspections each year. Plus, they maintain the very active parents and relatives programs With the community-based effort there, it is a two-way street; it is not only through the licensure process but through the community and through another unit of government.

And this is a good feedback mechanism for a State legislator like me, because if one is mad at the other, as you can well imagine, we are first to hear about it.

Senator DURENBERGER. Barbara, do you want to add to that?

Ms. MATULA. Well, in the medicaid nursing home program, every medicaid recipient must be seen once a year to assure that that quality of care is being met, that that plan is in effect.

The commitment from the Federal Government is open ended, so I would say that it is a question of supplementing that with an onsite ombudsman team, which most States have.

Senator DURENBERGER. So you have a once-a-year requirement, and then you have public health making sure the place is clean, or something like that? There ought to be something in between that.

Ms. MATULA. Right.

Dr. CARL. Senator, in Rhode Island we require that people have at least a monthly visit by an independent person, what we call a service coordinator. We also have, twice a year, a team of professionals that visit each one of these kinds of living arrangements, and we treat the arrangements the same, both in the institutions and in the community.

Senator DURENBERGER. How do you finance that?

Dr. CARL. How do we finance it?

Senator DURENBERGER. Yes.

Dr. CARL. We finance it through both the medicaid program, where we have eligible clients and eligible services—and those are either the medicaid waiver arrangements or ICF/MR arrangements. Where we don't have Federal dollars, then we finance them directly through the State appropriation process.

We have been able to work I think quite well with the medicaid program and capture a great amount of Federal dollars to assist us in the provision of these kinds of quality services.

Senator DURENBERGER. Thank you.

Any other questions?

Senator CHAFEE. Let me ask you two question, Mr. Gunther.

Well, perhaps I should ask the first question of Senator Bloom. I should think the community-based settings would help encourage more frequent visitations of parents, friends, and family.

Senator BLOOM. Absolutely. In the Peoria area, P.A.R.C.; we have allied agencies where various combinations of disabilities and retarded are serviced—Knox County Mental Health—all cut additional traveltime and expense.

Senator CHAFEE. As opposed to an institution—and I don't use the word "institution" derogatorily, but it's a word for the bigger facility—which is probably some distance?

We had testimony earlier indicating that the closest one to Chicago, at least in the last decade, was 140 miles?

Senator BLOOM. That is not accurate.

Senator CHAFEE. That is not accurate?

Senator BLOOM. Not at all accurate. There are two of them——

Senator CHAFEE. Well, in any event, you get some advantage with the community setting where the families can visit more easily. Is that a fact?

Senator BLOOM. Oh, no doubt about it. But each of these institutions—and you are going to find out, if those audience noises I heard behind me are accurate—has its own set of parents groups that feel very strongly. Dixon, Bowen, Kankakee Mantino, and now Galesburg in Illinois are closing, and I can promise you that, as I said, the Illinois Association of Retarded Citizens' group is profoundly split, and you are going to find that there are people, especially since, as I think one of the prior witnesses referred to, the upgrading of some of these institutions and capital expenditures, to keep the certified beds, there are parents groups that have developed a very strong attachment to these institutions.

As you can well imagine, there are intense emotions that have been generated in Illinois, having four institutions close. There are still too many beds for people, and Galesburg was split between the mentally ill and the developmentally disabled. No one has said how S. 2053 is going to address the problem of dual diagnosis.

I assume that the long phasein period is to somehow say to the States that you recognize the fact that they have made a hell of a capital investment over the last 7 or 8 years.

Senator CHAFEE. Thank you.

Mr. Gunther, briefly describe the kind of screening process you go through. Suppose you have a situation where the parent doesn't want the child to be moved to the community? What happens then?

Mr. GUNTHER. First of all, Senator, let me say that in 1978, at Ladd Center, we were experiencing the same kinds of things the Senator was describing, with parents being very fearful and very against having their children or relatives leave the center and going out into the community. They feared there would not be sufficient staffing; they feared for safety; "They don't have pedestrian skills; are you going to put them in a neighborhood where they will get hurt? How are you going to run these?" They are comfortable, and they feel they have done the right thing for many, many years in having their relatives stay there, and all of a sudden we come along and say, "Look, we are going to move these folks out."

When we said that to the Ladd Center Parents Association, we experienced all of those. But I said to them, "Look," talking about the process, "I am not going to say to you we are just going to willy-nilly send people out. If I cannot convince you, in your own mind and heart, that this is a better place for your son or daughter or relative, then certainly I am going to take a step backward."

And as each situation came along, as each home opened, I would bring the parents there and show it to them and talk about the kinds of staffing.

By the way, we don't staff group homes in terms of a geometric equation; you look at the clients who are going to live in the group home and determine the kind and amount of staff that is required. So in saying there is never enough staff, we staff them according to what each person needs, so the staffing is always different in different places.

So once the parents begin to understand this, they see the supervision that is going to be in place—three shifts, 7 days a week, very similar to the institution—that's how we deal with it. When the parent says, "No, absolutely not," then we have a discussion with my superior and the parents, and we continue to talk it over.

In the 5 years that I have been operating this program and moved hundreds of people out of the institution to the community, there has never been one instance where the parents have objected. Where they have objected initially, I just did not move at that time. I waited until they felt comfortable, and we worked it out together. And I have never had a case in the final analysis where they didn't go.

Senator Chafee. Have you had any situations where people have been moved to the community and then the parent or the relative or the guardian, wants to move the person back to the institution?

Mr. Gunther. No, sir, I have never had that. We have had three or four clients who have returned to the institution because they just did not make out well, just did not fit in, were not happy there, and so we returned them. That kind of what we call the recidivism rate, the return rate, is not very high, however, which I think goes into a lot of the planning on the front end, making sure we take our time and transition these people with their families in a very careful manner.

Senator Chafee. Thank you.

Thank you, Mr. Chairman.

Senator Durenberger. Thank you.

Any other questions?

[No response.]

Senator Durenberger. All right. Thank you all very much for your testimony. I appreciated it a great deal.

Our next panel consists of Robert Decker, executive vice president, Chartham Management, Salem, Oreg., on behalf of the American Health Care Association; Margaret L. Shreve, executive director, the Whole Person, Inc., Kansas City, Mo.; Guerin A. Fischer, executive director, Clearbrook Center for the Handicapped, Rolling Meadows, Ill.; Sister Barbara Eirich, director, Community Resource Center for the Developmentally Disabled in the Bronx, N.Y.; and Thomas Broacto, counsel, on behalf of St. Mary's Training School for Retarded Children in Alexandria, La. Do we have Sister Antoinette Baroncini here, also? Oh, there you are. All right.

Is there anybody who is here that I haven't called off, or anybody that I should call off that is here?

[No response.]

Senator **Durenberger**. We will begin the testimony by indicating that all of your written statements will be made part of the record with our appreciation for the time and effort that went into preparing them, that you may summarize those statements in 2 minutes or less, and that we all appreciate the distance you have come and the effort you have put into providing us with assistance.

We will start with Mr. Decker.

STATEMENT OF ROBERT DECKER, EXECUTIVE VICE PRESIDENT, CHARTHAM MANAGEMENT, SALEM, OREG., ON BEHALF OF THE AMERICAN HEALTH CARE ASSOCIATION

Mr. **Decker**. Good afternoon. My name is Robert Decker, and I am the representative of the American Health Care Association, the Nation's largest federation of long-term care facilities.

AHCA opposes Senate bill 2053. The fundamental problem with the legislation is that it provides only one type of dwelling for the mentally retarded and the developmentally disabled individuals whose problems are both diverse and complex.

In the late 1800's and early 1900's we built only large public institutions, and recommended placement of all mentally retarded in those institutions. We now know that the mentally retarded have a wide range of needs and require more than one method of treatment. Senate bill 2053 would limit the settings for the delivery of care to one type of setting and therefore restrict the modes of treatment.

AHCA believes that a continuum of care, including State institutions, facilities of 16 or more residents, as well as smaller group homes, semi-independent and independent living situations, must exist to adequately meet the needs of these individuals.

The proposed program will increase the cost of care, and the preliminary Congressional Budget Office report on cost savings must be challenged. New construction costs were not included in their report, and we estimate them to be over a billion dollars. The cost of expanding medicaid coverage to include vocational training has not been included. The report does not account for the expansion of eligibility from the current definition of "developmentally disabled" to "severely disabled."

It is unclear whether the increased costs of managing, administering, and enforcing a program which is scattered throughout many locations is included.

It is unclear whether the costs are adjusted to account for the higher costs of the heavy-care residents now residing in the larger facilities. And it is unclear whether the costs of care not now included in group homes per diems but allocated to other cost centers were even considered.

AHCA recommends the following:

That the States utilize the section 2176 of the medicaid home and community based waiver program to develop community care programs, and that that section 2176 waiver program be studied for its effectiveness before the drastic changes or additions are made to the medicaid program.

Thank you.

[Mr. Decker's prepared statement follows:]

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AMERICAN HEALTH CARE ASSOCIATION

Testimony Before
The Senate Finance Committee Subcommittee on Health
On
"The Community and Family Living Amendments Act"
S. 2053

Delivered by

Robert Decker
AHCA Task Force on Care of the
Developmentally Disabled

February 27, 184
Washington, DC

A non-profit organization of proprietary and non-proprietary long term health care facilities dedicated to improving health care of the convalescent and chronically ill of all ages. An equal opportunity employer.

Good morning. My name is Robert Decker. I am here today representing the American Health Care Association and its Task Force on the care of the Developmentally Disabled. I am also the Executive Vice President of Chartham Management Inc, a private corporation which owns and administers five intermediate care facilities for the mentally retarded in the Northwest. My past experience includes four years as the superintendent of the Idaho State School and Hospital, a public facility for the developmentally disabled. In addition, I have experience as a foster parent to a developmentally disabled individual.

INTRODUCTION

The American Health Care Association is the nation's largest federation of long term care facilities. Over 8,000 member facilities provide care to the chronically ill and developmentally disabled of all ages. We appreciate the opportunity to offer our comments on S. 2053, the "Community and Family Living Amendments Act of 1983." The proposal would require that all Medicaid funds for residential services be transferred from mid-sized and large institutional settings to small facilities which serve a maximum of eight or nine clients. AHCA believes this proposal would have a detrimental effect on programs serving the severely disabled. More importantly, the proposal would adversely effect the developmentally disabled who require special services in order to acquire skills needed to live as independently as possible.

BACKGROUND

In 1972 Congress extended Medicaid coverage to include ICFs/MR. Active treatment and twenty-four hour supervision are required for certification. In 1975, rules were issued to implement the program. The goal of the ICF/MR program is to help each developmentally disabled person reach his/her maximum potential. Each resident must have an individual active treatment and training program. Active treatment is a planned, goal-oriented therapy program which assumes the resident can develop beyond current capabilities.

Under the Medicaid rules, ICF/MR facilities are licensed and monitored by states. They must meet extensive Life Safety Code provisions, local fire and zoning laws. Five hundred and sixty specific federal standards govern ICF/MR facilities. In addition there are state certification, licensure and program standards. Facilities are inspected for 1) quality of programming and treatment of residents, 2) physical safety and sanitation, and 3) utilization review to determine if the level of care is appropriate to meet the residents' needs.

Professional services offered to residents include nursing, dental, medical, psychology, physical therapy, occupational therapy, speech pathology, audiology, therapeutic recreation, pharmacy, social and dietary services. These services are part of the "total" care the large and mid-sized facility provides to its residents.

The ICF/MR program serves persons with a broad range of disabilities, such as blindness, cerebral palsy, epilepsy, and mental retardation. Many ICF/MR residents have no next of kin. A sizeable number of children are "wards of the state."

P.L. 95-602, enacted in 1978, defines developmental disabilities as:

a severe, chronic disability of a person which:

1. is attributable to a mental or physical impairment or combination of mental and physical impairments;

2. is manifest before age 22;

3. is likely to continue indefinitely;

4. results in substantial functional limitations in three or more of the following areas of major life activity:

    a) self-care
    b) receptive and expressive language
    c) learning
    d) mobility
    e) self-direction
    f) capacity for independent living, or
    g) economic self-sufficiency; and

5. reflects the need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are:

    a) of lifelong or extended duration and
    b) individually planned and coordinated (Public Law 95-602, 1978)

One must meet all five of these criteria to be classified as a developmentally disabled person.

There are four types of locations of the delivery of care for the developmentally disabled. The majority are cared for by their families in the home and receive treatment through special health education and training programs.

Other developmentally disabled are cared for in ICF/MR facilities. Six to fifteen percent of all mentally retarded live in some form of supervised residential setting such as state institutions, private mid-sized ICFs/MR, and foster care or small community facilities.

At the present time a state has the option to operate an ICF program. Some state Medicaid programs support only state institutions and small programs; however, others support mid-sized programs as well.

There is a trend toward developing community care facilities. For example, over the last decade the total population of large state institutions has declined by one-third while the number of community care programs has increased ninefold. New admissions to supervised apartments during 1982 increased by 31.9 percent while new admissions to large facilities grew by 6.4%. One third of the existing small programs have opened since 1980. The Section 2176 Medicaid waiver program to fund home and community based services is expected to accelerate the growth of group homes and use of community based services.

AHCA POSITION ON CARE OF THE DEVELOPMENTALLY DISABLED

AHCA supports a wide spectrum of services for the developmentally disabled and advocates a system which provides service delivery through an assortment of settings tailored to address the needs of the individual. AHCA opposes the "Community and Family Living Amendments Act of 1983" proposal to limit reimbursement for services to a single model of service delivery. The needs of the developmentally disabled are diverse and must be addressed by a variety of systems and programs.

For some developmentally disabled persons a small facility may be ideal. For others, especially those with numerous complex problems, a larger facility that can offer an array of services and full staffing is more appropriate. If all facilities are limited in size, no single facility will be able to provide a wide array of services. This will cause particular problems for the severely handicapped who need multiple services such as professional nursing services, physical therapy and occupational therapy and other special consultation and direct care.

Many statements will be made here today citing studies and programs which support the theory that small community based facilities are less expensive than institutional care. These statements are misleading. In order to correctly interpret them one must understand the various levels of care that are provided for ICF/MR clients.

Two types of facilities comprise "institutional care facilities." This fact is not usually apparent in cost studies. There are the large state facilities and the private ICF/MR facilities such as those which are AHCA members. Large state run facilities are often the most expensive. In part, this is because of higher labor and, property costs and the higher costs associated with the heavy care clients they service. These facilities often cost over $100 per day. AHCA member facilities are private proprietary and non-proprietary facilities which range in size from 16 beds to 200 beds but are usually approximately 50 beds. Reimbursement is approximately $50 to $65 dollars per day per resident. Problems arise when the costs of these levels are lumped together. Such a practice leads to the assumption that all institutional care is more expensive than community care.

A second problem pertains to the term "private ICF/MR", which may be misleading. Sometimes it refers to small community-based facilities caring for up to 15 clients. Other studies define private ICF/MR care as mid sized institutions caring for up to two hundred clients.

The lack of uniform definitions causes problems when the average per diem costs are discussed. Small (up to 15 beds) facilities often utilize training, education, social services, and therapy programs which are supported through state and county governments, United Way and charitable donations. The costs of these services are not necessarily included in the "per diem". Mid-size and large facilities usually provide comprehensive services on campus as part of the facilities' program. The costs of these comprehensive services are included in the perdiem rate.

Studies which compare institutional and community-based care do not treat the mid-size facility and its costs and services as a distinct model of care. This could mistakenly lead one to believe that mid sized facility costs are as high as the public institutions or that their costs are higher than community-based facilities which utilize outside programs.

SUMMARY OF "COMMUNITY AND FAMILY LIVING AMENDMENTS ACT"

The legislation would shift Medicaid funding for the care of severely disabled individuals from institutions (ICFs/MR, SNFs/MR, ICFs and SNFS) to community living arrangements. The deinstitutionalization program would be phased in over ten years for most institutions and fifteen years for relatively new institutions caring for 15 to 75 clients.

Severely disabled individuals are defined as individuals with developmental or physical impairments or both, which are manifest before age 50, are likely to continue indefinitely and result in substantial functional limitations in three or more of the following areas: self care, language, learning, mobility, self direction, capacity for independent living and economic self sufficiency. This would include many mentally retarded, the developmentally disabled and many head injured individuals.

Community living facilities would be limited in size to 8 or 9 beds, must be in residential areas but cannot be clustered and must meet safety standards. Written individual plans of care are required, as is training for staff. Medical assistance, home and community based services, vocational services, case management and monitoring are authorized. Access to habilitation and rehabilitation, social and educational services is required. Facilities are required to be licensed or certified or accredited by the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons. Federal Medicaid payments would temporarily increase by 5 percent of the total amount expended under the state plan for the care of individuals transferred from institutions to community care. There is a 5 percent reduction in the Federal Medicaid match for non-complying facilities and institutions.

AHCA POSITION ON S. 2053, THE FAMILY AND COMMUNITY LIVING AMENDMENTS

AHCA is opposed to the Community and Family Living Amendments. The bill would withdraw funding from good facilities which are providing comprehensive services that enable a developmentally disabled person to learn the skills needed for independent living and transfer funding to facilities which have an unknown capacity to care for the developmentally disabled and which are dependent upon outside, piecemeal funding sources.

S. 2053 "THE COMMUNITY AND FAMILY LIVING AMENDMENTS ACT"

The fundamental problem with the proposal is that it is based on unsound, unproven and clinically unacceptable premises.

Our objections are centered on the following major points:

1. Not all severely disabled persons can be cared for in community settings.

2. Quality is not related to size. Big is not necessarily bad and small is not always good.

3. Mandating community care for all severely disabled persons will increase the cost of care.

- Not all severely disabled persons can be cared for in community settings.

  - Many severely disabled are physically and mentally handicapped and suffer from life threatening medical conditions. Some are frail and need constant observation by professional staff. For example, some of these individuals have many seizures daily. The administration of medications, shunts, tube feedings require professional staff.

  - A large portion of institutionalized mentally retarded residents also suffer from serious behavioral problems. These people require a high staff ratio and intense care by trained individuals. Access to professional help is a necessity for both staff and residents. Experience shows that these clients are the most difficult to place in community care, that they are among the most expensive to care for and that emotional and behavior problems are directly related to recidivism.

  - Some past deinstitutionalization of the severely disabled people have failed miserably. Efforts in Kentucky and Florida are examples of inadequate care, high mortality rates and irreversible damage. In these cases, it is always the disabled who pay the price.

- Quality is not directly related to size.

  - Larger facilities can provide more services and are in better positions to develop a professional staff to deliver varied and complex sophisticated services. Because of the nature of the funding source for large facilities clients are less dependent upon varied and categorical program appropriations which can be changed or terminated. Such changes can disrupt or cancel services.

  - Numerous studies have concluded that size is not related to quality of care and that home like facilities do not guarantee improvement in behavior of either staff or studies.

  - Several studies have evaluated family style homes as more restrictive than larger settings.

- At least one study comparing small and large settings found that in larger facilities residents engage in more social behavior and develop more friendships than residents of small facilities. Another concludes that larger facilities are more likely to utilize agencies services and programs and thus appear to be closer to the objective of client normalization and developing social competence than smaller facilities are.

- Larger facilities, by virtue of large professional staffs and large number of visitors allow for greater opportunity to formally and informally monitor resident care.

- The life safety of disabled people is enhanced through physical structures built or modified to meet life safety and other code requirements developed to provide needed protection. Family homes are not designed to provide this protection.

o Mandating community care for all severely disabled persons will increase the cost of care.

- The Congressional Budget Office report showing a cost savings must be challenged. It is difficult to determine what assumptions were used in developing the report. However, it appears that large costs were not included.

- An example is the cost of new construction. Cost figures are based on a projected discharge rate of 12,000 residents per year. This will require over 1,500 new group homes per year. Experience shows that it is cheaper to build new group homes than to retrofit existing dwellings. Current new construction costs are $25,000 to $30,000 per bed. Between $3 and $3.6 million, plus interest and depreciation, would be needed each year. Over $1 billion would be needed just to build group homes for the current residents of state institutions who would be deinstitutionalized. States are currently having difficulty raising bonds; moreover, many bonds that were raised over the last decade for large institutions have not been retired. Some states are placing lids on cost per bed which would prohibit new construction at current costs.

- Other costs not clearly included are:

  1. Additional costs of administering, monitoring, surveying and inspecting a greater number of facilities scattered throughout the country.

  2. "Start up" costs which would be associated with the program. These should include the cost of maintaining the empty bed at the large facility. Costs associated with the additional number of staff who will be needed to fill gaps in the delivery of services caused by time spent traveling to, from and

between facilities. Labor costs are currently approximately two thirds of the program costs.

3. Costs of caring for the new population who would be included in the definition of severely disabled. We believe it would include many head injured victims. These people are generally heavy care residents, needing intense therapy, nursing and supervision.

4. Costs of adding authorization of vocational rehabilitation costs under Medicaid.

5. Costs of transportation to services may also need to be included.

6. Costs of deinstitutionalizing the heavy care resident. Approximately one half of the institutionalized are multiply handicapped, one-third are non-ambulatory and one-third suffer from emotional problems. To date, most community care programs care for less handicapped persons.

-- Some severely disabled may be cared for in community settings for less dollars. However, we find this rarely to be true. Several factors should be considered when calculating expenditures.

1. In community care costs for services are distributed among different cost centers or funding programs. For example, transportation, day programming, therapy and workshops are often funded out of education, Title XX, state county or local funds. At the same time, institutional costs are usually the total cost.

2. Information on reimbursement of private ICFs/MR (such as those which belong to AHCA) compared with small programs is not available for each state. However, as the following examples show, community care can be more expensive.

Kansas

Large facilities	less than 15 beds
$39.53 per day	$50.54 per day

Idaho

30 bed facility	11 other facilities ranging from 5 to 24 beds
$54.38 per day	$73.79 (average per day rate of 9 facilities)

Michigan

SNFs/MR	community program
$56.00 per day	$94.00 per day

Kentucky

Private ICF/MR	community care
$23,000 per year	$40,000 per year

There are other concerns which need to be considered in the impact of this legislation.

- As written, this legislation would also affect the care of the "head injured" patient. These people are usually the victims of accidents such as auto crashes, drug overdoses and gunshots. They fit the definition of the developmentally disabled as outlined in Section 1918(h). In many cases, these individuals are cared for in nursing homes. Some are comatose and semi-comatose and require daily nursing and therapy services. Cognitive retraining, respiratory care, tube feedings and sensory stimulation are professional services which are often required. These services cannot be effectively provided in small settings.
- What would be the impact on the cost of care if states opt to include those severely disabled whose families spend up to five percent of their adjusted gross income on care? Isn't this adding a population that is not necessarily financially needy?
- What states rights issues would be generated by a program which is mandated by the federal government, but is also part of the Medicaid program which is supposed to allow flexibility to states to design and provide services according to the needs of its population?
- There is no provision for the rights of the disabled and their families who prefer the institutional care model. These people must have the right to choose or at least influence the choice of care.
- The intent of the legislation is for a gradual phase out of institutions. Private ICFs/MR and SNFs/MR must make ends meet. The break even point is not too far below full capacity. Many of the residents would be sent to institutions until community care is available. Each transfer causes a disruption in services to the client. This could result in a loss of skill development.
- Recidivism is a fact. Under this proposal, clients would have no where to return. How will these people be handled - will they be transferred from one community program to another and eventually fall through the cracks?

- What about investors who have risked private capital to develop mid sized private institutions? How (or will) they be compensated? Many private companies were approached by the state and asked to establish mid sized facilities.

- How would the 5% increase per person affect implementation of the Sec. 1915 Medicaid waivers for home and community based care? The waiver money can only be used to support community care if the average cost of that care is less than the cost of institutionalization. Would this create two classes of community care recipients?

- How will the five percent be calculated? Will it be based on the per diem rate for the facility the person was previously in or the average per diem rate for the state?

- Who would be responsible for maintaining closed institutions? Even closed facilities incur costs. Billions of dollars have been spent in the last few years to improve these facilities.

- The bill assumes that there will be group homes available. Who will be responsible for acquiring or building the homes?

- There is no doubt that Medicaid funding and standards have improved care in ICFs/MR of all sizes. If it is withdrawn from large institutions and if the state must maintain the institution we may see a recurrence of problems which existed prior to the early 1970s. If Medicaid funding is not provided, Medicaid standards will not be required to be met.

- Previous efforts to restructure care for the mentally ill have failed. In the mid 1960's, national effort to deinstitutionalize over crowded, large mental hospitals was implemented. Plans to serve the deinstitutionalized through community-based resources did not materialize. The result was a rapid and unplanned exodus of thousands of state mental hospital patients which caused a shift of the location of the chronically mentally ill to the community without the concurrent shift in sufficient community services or resources. As a result, many of these people were unable to live independently and were forced into substandard boarding homes or shelters for the homeless. Others have been placed in nursing homes which are not always able to provide the care needed. Transfers to appropriate care settings are usually difficult because of an insufficient bed supply in those settings.

AHCA RECOMMENDATIONS

1. The Senate Finance Committee should not mark up or report S. 2053. For the reasons listed above, the proposed program would be detrimental to the care of the severely disabled.

2. States should utilize the Sec. 2176 Medicaid Home and Community Based Waiver Program to develop community care programs. The program provides needed flexibility and funding for effective, community care.

3. The Sec. 2176 waiver programs should be studied for effectiveness before any drastic changes are made to the Medicaid program.

CONCLUSION

AHCA cannot endorse the proposed system. It is based on an arbitrary size and premised on unproven theories. If enacted, we foresee many ex-residents of facilities isolated in small homes, uncared for and eventually forgotten or ignored.

Any changes in Medicaid must encourage a balanced approach to the care of the severely disabled. While the severely disabled have one thing in common -- disability -- they are a heterogeneous group and cannot all be pushed into a narrowly designed system which works under certain circumstances.

There is a need for small facilities. For those who can make the transition from institution to community, small home like facilities can ease the way. Unfortunately, many people are unable to develop the skills necessary to live independently. These people may be profoundly retarded, blind, crippled and suffering from any number of medical conditions. These people need nursing and therapy and custodial care 24 hours a day in addition to training. Is it practical or even possible to provide these services in small scattered settings? Even if the personnel were available, the cost would be prohibitive. The total cost of a nursing visit, a home health aide visit and a therapist visit could be as high as $80 per day. Add to this the cost of room, board and custodial care and the total cost is much more than what Medicaid now provides.

AHCA is concerned this legislation will appeal to those who are not well informed yet who support its goals. We support the goal of independence; however, we know the proposed system will be disastrous for the developmentally disabled. They need and deserve more than a system which is based on an arbitrary number of beds, not the quality of services.

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Senator **Durenberger**. Thank you very much.

Let's see, I guess next is Margaret Shreve.

Hi, Margaret.

Ms. **Shreve**. Yes. I've come off the snow bank in Maryland, and I'm now here.

STATEMENT OF MARGARET L. SHREVE, EXECUTIVE DIRECTOR, THE WHOLE PERSON, INC., KANSAS CITY, MO.

Ms. **Shreve**. I am here to represent physically disabled people, and particularly those folks living in Kansas and Missouri. I am the director of a center for independent living called The Whole Person.

The people that I am concerned about are folks who have arthritis, who have cerebral palsy, who are blind, deaf, with multiple sclerosis, muscular dystrophy, et cetera. And most of the individuals that my program and others like mine serve are people who are severely, permanently physically disabled, medically stable, and mentally competent. We support the bill.

We have some concerns about the bill, and the four largest concerns are the age limit, the degree of consumer control which can be exerted over a medicaid service, the living arrangements, which according to the current text are somewhat restrictive, and I think that is due to the fact that they were written for community-based facilities, and that the definition of "natural homes" should be expanded so that it includes choice for the severely physically disabled person, such as living alone, living with friends, living with spouse, dependents, and any arrangement thereof.

An example of the current problem we have in the State of Missouri is that we have no in-home personal care services under medicaid for more than 60 hours per month. For a severely physically disabled quadraplegic person, that is not sufficient; therefore, the only alternative is a nursing home.

We are working right now in Kansas City with someone who is a spinal cord injured man, 18 years of age, who does require 24-hour attention because he is on a respirator. But no nursing home will take him, and if he doesn't leave the State and find the services that he requires in his own home, he is probably not going to survive.

We have the technology to make sure that people with this level of disability survive, but we are not providing the in-home or the community-based services to make sure that they have the quality of life that they deserve.

Programs like mine are working on issues like accessible housing, accessible transportation, public accessibility in the sense that our public buildings are more wheelchair-accessible, communication accessible, et cetera.

The thing that we seem to be lacking the most is the personal care, the in-home service, and it has to be individualized, tailored to the individual's level of functioning and level of physical disability. And that is why we therefore support the bill.

Thank you.

Senator **Durenberger**. Thank you very much.

Guerin Fischer.

[Ms. Shreve's prepared statement follows:]

The WHOLE PERSON Inc.

SUMMARY OF PRINCIPAL POINTS

contained in

Testimony for S. 2053 by Margaret L. Shreve

I am representing the interests of severely physically disabled people from the states of Kansas and Missouri in support of S. 2053, the Community and Family Living Amendments of 1983.

This bill could provide for the community-based, in-home services needed by severely physically disabled persons in order to live independently in the community settings of personal choice. The bill needs to address several concerns which were apparently overlooked in regard to the physically disabled population. These concerns are:

1) Lifting the age restriction so that persons who incur a permanent physical disability after age 50 are eligible for community-based services.

2) Defining "natural home" to include many options such as living alone, living with friends, living with spouse, living with dependents, or any combination of such living arrangements.

3) Removing restrictive language in reference to where a severely disabled individual can live.

4) Expansion of consumer involvement throughout requirements of the bill; including disabled people in the planning of community-based services as well as implementation and supervision of such services where possible.

Like the developmentally disabled population, severely physically disabled persons are often placed in institutions for lack of any alternative. If a major funding mechanism can be used to reverse this situation, severely physically disabled people could live independently in the community with minimal support services. The severely physically disabled population does not need community-based facilities or "bricks and mortar" projects but does need individualized and personal services in the home setting of their choice. Senate Bill 2053 could provide this.

Advocates for severely physically disabled people look forward to passage of Senate Bill 2053 and thank the Subcommittee for the opportunity to speak in the bill's favor.

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The WHOLE PERSON Inc.
WP

TO: Senator Dave Durenberger, Chairman
Subcommittee on Health of the Senate Committee on Finance

RE: Testimony for S. 2053, The Community and Family Living Amendments of 1983

DATE: February 21, 1984

I am Maggie Shreve, Executive Director of The WHOLE PERSON, Inc. in Kansas City. The WHOLE PERSON is a community-based, non-residential service and advocacy organization for people who have severe physical disabilities. I am testifying for Senate Bill 2053 as a representative of various consumer groups of physically disabled people in Kansas and Missouri. We believe that Senate Bill 2053, the Community and Family Living Amendments of 1983, has tremendous positive implications for severely physically disabled people who are struggling to live independently in the community.

The population to which I am referring is composed of individuals who have severe physical limitations but are mentally competent. This group includes many types of physical disabilities such as arthritis, blindness, cerebral palsy, deafness, head injury, multiple sclerosis, muscular dystrophy, polio, spina bifida, spinal cord injury, stroke and similar disabling conditions. As a representative of this group, I have concerns about some language used in Senate Bill 2053. I am concerned about the age limitations used in the bill; the definition of "natural home;" the degree of consumer control which can be exerted over the types of services to be covered by Medicaid funds; and the definition of the type of neighborhood in which a severely disabled recipient of Medicaid funded services can live.

It is obvious that Senate Bill 2053 was drafted to respond to the non-institutional service needs of developmentally disabled persons. I see the same potential for people with severe physical disabilities but in different ways. First of all, I do not assume that severely physically disabled people need "bricks and mortar" projects specific to their disabilities or their needs. I assume that a broad spectrum of community-based, in-home services which are tailored to each individual's level of physical functioning and management abilities are needed. Secondly, I do not assume heavy involvement from parents or guardians but rather reliance upon the consumer him or her self regarding the planning, implementation, supervision, and evaluation of community-based services.

Many severely physically disabled people are able to live in the community if certain environmental changes are made and necessary supportive personal services are available. These services are not housed within a "facility" of any specific type but need to be provided to the individual in his or her choice of residence. One such typical service which is not readily available in this country is Personal Care Assistance or PCA. A frequently used definition of Personal Care Assistance services is a consumer-directed, in-home service which allows for up to 42 hours of service per week and in which the consumer recruits, interviews, hires, trains, manages, and discharges his or her attendants (or PCAs). Senate Bill 2053 could provide the

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funding mechanism needed for the establishment of Personal Care Assistance services.

Based upon these general issues, the physically disabled population will benefit from Senate Bill 2053 if certain sections of the bill can be clarified. Below are those sections which will require additional attention in order to meet the needs of severely physically disabled persons while maintaining a cost effectiveness compared to institutionalization.

Section (c)(1)(A) should include skilled nursing facilities as well as intermediate care facilities and institutions for the mentally retarded.

Section (c)(1)(C) may be too limiting if only section 702(b) of the Rehabilitation Act of 1973 is used. We would add general language which addresses the need for any community-based service which is necessary for the health and well-being of a severely disabled individual living independently in the community.

Section (h)(1)(B) should not be restricted to age 50 as the cut-off for onset of disability. Some advocates believe that 65 is a more appropriate age. I personally believe that this bill has great potential for disabled elderly individuals as well as other age groups and should not contain any upper age limits at all.

Section (h)(1)(E) assumes that the Medicaid recipient is in need of more than one service which may not be the case. This section should include the possibility that a severely disabled person may need only one service from Medicaid.

Section (h)(2) should provide a definition of "natural home." Typical developmental disability policy and language limits "natural home" to a residence where a parent or guardian is in charge. For the severely physically disabled adult who wants to live alone this would not be appropriate. We therefore suggest that a definition of "natural home" include the possibility of living alone, living with friends, living with spouse, living with dependents, and any combination of such possible living arrangements.

Section (h)(2)(C)(ii)discriminates against the severely disabled individual who wants to select where he or she will live. This section was presumably written for the establishment of group homes or other community-based facilities but needs to be broadened. It should not restrict an individual's choice in the selection of a living site.

Section (h)(2)(D)(i) needs further definition so that it includes involvement of the consumer or Medicaid recipient. In reference to the Personal Care Assistance concept mentioned above, the only disciplinary team required for implementation of the service may be a social worker or occupational therapist who performs an in-home evaluation. Some services may not require interdisciplinary teams while others might. Adding the consumer to the team's membership, as appropriate, may eliminate this problem.

Section (i)(1)(C) should be expanded to include consumer involvement and/or representation. This would allow for the training of certain care givers by the consumer as in the Personal Care Assistance example.

Section (i)(1)(I)(ii) is somewhat unclear. We read this section as requiring peer or consumer involvement in the planning process; but during a second reading, we realized that it refers primarily to professionals in the delivery system. We would prefer to see consumers involved in order to continue emphasis of consumer control where possible.

Section (i)(1)(J) and (K) appear to have omitted the severely disabled individual in error. The consumer should be the first person contacted in both the decision making process and in the appeals procedure.

In summary, those of us involved in the provision of community-based servcies to severely physically disabled persons see Senate Bill 2053 as the answer to many of the planning and service delivery problems which now occur on the local level. It would reverse the current funding situation which does not permit for community-based in-home services in many instances. This current problem results in many unneeded and costly institutional placements of severely physically disabled citizens who could be fully participating in their chosen communities.

We also see the need for changes to the existing bill so that it can adequately meet the needs of the severely physically disabled population in the most cost effective manner possible. Changes in the age limitation, definition of "natural home," delineation of where a consumer can live, and the expansion of consumer involvement in all aspects of service delivery will strengthen this bill. We hope that the Subcommittee on Health and eventually the Senate Committee on Finance will see the merit of this bill and seek its passage. Thank you for your time and attention. If further information or clarification is needed, please do not hesitate to contact:

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STATEMENT OF GUERIN A. FISCHER, ED.D., EXECUTIVE DIRECTOR, CLEARBROOK CENTER FOR THE HANDICAPPED, ROLLING MEADOWS, ILL., ON BEHALF OF THE VOICE OF THE RETARDED

Mr. FISCHER. My name is Guerin Fischer, and I am representing the Voice of the Retarded, a large group in Illinois that is made up of 28 various parent groups, representing about 8,000 parents in Illinois. It is a very new organization that came upon the scene shortly after we had more news with regard to S. 2053.

I also am the executive director of Clearbrook Center for the Handicapped, a large facility in suburban Chicago that has 14 different sites and has about 450 people from ages zero to adulthood. We have a variety of services, including many group homes and also some large facilities.

On behalf of the group I am here today to represent, I want to make a few comments and give some examples.

We are opposed to the bill because, based on the premise that care can only be delivered appropriately in a very small, less than 10 environment, we maintain that some forms of developmental disability demand special technologies and specialized staffs which are only available in larger facilities, and by "larger" I am talking about larger than 10.

The phasing out of residential facilities that house more than 10 people is being promulgated without the assurance that community-based facilities are available.

Let me give you an example: There are only at the present time 16 group homes in Illinois, four of which are managed by Clearbrook Center for the Retarded. No start-up money, Senator, which you asked earlier, was available to purchase the homes and start them up, as far as capital purchase monies from the State of Illinois.

The parents who were interested in going to this new concept were the ones who started the fund raising, and, incidentally, 60 percent of our budget comes from the State of Illinois. For 40 percent we do our own on fund raising, which also we feel very strongly would have a direct implication should this bill be passed.

So back to your question about the capital. No, we have not received capital funds for our group homes, nor have we received capital funds for a facility that we are currently building that would house 90 people in a residential area in suburban Chicago, that would happen to be clustered, with 15 people per cluster and 6 total clusters, which also would be eliminated should this bill be promulgated as it is currently written. We have very strong feelings about the cluster concept.

Now, for a minute, on costs. Please do not be persuaded or too sure about some figures you have perhaps heard as far as the cost of group homes in the community versus State facilities.

We have taken people from the State institutions, and our current costs in our group homes run at $85 a day versus $100 a day, which is what the State is paying now in Illinois. And we are talking about mild and moderate individuals, higher functioning retarded people. And so I think you have to see the association between starting putting other types of important people in the community, the profound and severe which only make up 5 percent of the total population out into the community, and you can add the difference of costs. There isn't that big of a difference; in fact, I would suggest that maybe the researchers should look at the individual agency's audits, like Touche Ross, different audits that we have, rather than looking at Government figures. And I think you might find more accurate figures amongst all of the States.

So we feel there is a tremendous need for the continuum of services, as was mentioned earlier. We are concerned about the State institutions, decent quality care, decent community care, and we all I think share that feeling very strongly.

Thank you very much.

Senator DURENBERGER. Thank you very much.

Sister Barbara.

[Mr. Fischer's prepared statement follows:]

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Hearing on COMMUNITY AND FAMILY LIVING
AMENDMENTS OF 1983, S. 2053

February 27, 1984

The President's Commission on Mental Retardation was appointed in May of 1966. As a result of this commission, some progress has been made in serving the mentally retarded but it is proceeding through a succession of small advances across the broad front, rather than by any singular spectacular advance. Unfortunately, little has been done in the area of residential services. Now we are faced with a proposed Senate Bill which, as written, could eliminate much progress that has been made these past 18 years.

SB 2053 is basically lumping all classifications of mentally retarded into one living arrangement, non-clustered group homes in the community with less than 10 people per home. By classification, I mean the Profound (0-19 IQ) or 1.5 percent of the retarded population; Severe (IQs between 20-34) or 3.5 percent of the retarded population; Moderate (IQs of 35-49) or 6 percent of the retarded population and the Milds or IQs of 50-69, 89 percent of the mentally retarded population.

There is merit in placing Mild and Moderate retardates in community based facilities if proper funding is available. Clearbrook Center for the Retarded has done just that. Clearbrook manages 4 of the 16 group homes in the State of Illinois. 484 more homes would be needed to accommodate the 5,000 State institutionalized people, not to mention another 8,000 retarded adults who are at home and will need an eventual placement as their parents or relatives become unable to manage them. Our annual Touche-Ross audit reveals that group homes are expensive, i.e. $85 per day for a person in a

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group home versus $100 per day for a person in a state institution. But please remember that the $100 per day is for service rendered to profound and severe clients. It costs more for that population which comprises only five percent of the total mentally retarded population.

From my personal experience, support services for group homes are not available and we are located in affluent suburban Northwest Chicago. We serve higher functioning individuals who need supervision and guidance, 24 hours a day; however, they can self-medicate, can be trained to cross an intersection, can be trained for possible fires in the home, etc. Staff turnover is a problem but manageable. It would become unmanageable if the clients were profound and severe.

SB 2053, as written, does not differentiate between the services that a good State institution provides, that good community-based ICF/DDs with 15 and over provide, or quality group homes. An example: Clearbrook currently is building a 90-bed ICF/DD in the residential community of Rolling Meadows, Illinois. It is a one-story, 41,000 square foot building accessible to ambulatory and non-ambulatory prople. It will have an indoor pool, bicycle trails, nursing care, doctors, six clusters interconnected with individual kitchens and laundry facilities. $2.1 million has been raised thus far, all as a result of the community-based parent oriented Board. No financial assistance has been received from the State of Illinois. The Illinois/ARC testified during the zoning hearings two years ago in support of the project. SB 2053 would put the ICF/DD out of business before it opened, because

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95% of the population would be Medicaid recipients.

We advocate a continuum of services. Please refer to the attached chart which systematically depicts a continuum of alternatives. We support the philosophy that espouses helping retarded people progress to another advanced level, which includes a less restrictive residential setting if they qualify and if facilities are available. But in contemporary Illinois, a minimum number of state residents could move to community-based facilities because the accommodations are not available for profound and severe people.

Another major issue is the question of costs. The provisions of SB 2053 would force the abandonment of a functioning system of quality care of the severely developmentally disabled individual. This abandonment would be based on isolated experiences that are said to prove that care can be provided more economically in settings of 10 or fewer clients. Proponents of SB 2053 have publicized what are purported to be comparisons of costs of services between large State-operated institutions and small community-based services. These comparisons show the cost of community-based services to be approximately one-half the cost of services provided in the larger institutions. However, Ronald Conley, an economist at the National Institute of Mental Health, cautions that "these comparisons depend on the categories of residents and the complex of services provided within or outside of the facility". It is wrong to take the average cost per resident of a large facility serving a developmentally disabled population which has a wide

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spectrum of needs - from minimal to very extensive and intensive - and compare that average cost to the average cost of a small community facility whose clients have a narrow spectrum of minimal needs.

Our attempts to procure cost data which compare characteristics of clients and kinds of quality of services have been unsuccessful to the point that we seriously doubt such data exist. Our request for a copy of the Congressional Budget Office preliminary cost savings estimated on SB 2053 (quoted in ARC/I information sheet) revealed that the study had been withdrawn because of errors. A conversation with a representative of the Hubert Humphrey Institute for Public Policy (also quoted by ARC/I) indicates that savings were achieved in a facility serving approximately 30 residents; however, it seems foolhardy to destroy a system serving many thousands on the basis of that limited experience. The Report of the President's Committee on Mental Retardation Past and Present (1977) states that "While there is little disagreement that the traditional institutional patterns of custodial care have been dehumanizing, there is disagreement on the question of economy and the comparative quality of community services presently available". The President's Committee also reported the conclusions of a three-state study prepared for the Department of Health, Education and Welfare: "The costs of services to developmentally disabled persons in State hospitals (sic) do not differ significantly from the adjusted, true

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costs of services in community settings provided both groups are provided with a full array of needed services."

Senate Bill 2053 would arbitrarily deny Medicaid funding to institutions which are now providing quality services to the developmentally disabled. It is discriminatory in that, by forcing the closure of institutions, it will eliminate a valid choice from among an array of settings in which services may be provided. ARC/US' Position Statement on "Least Restriction" states that this choice of setting should "involve a team consisting of professionals, parents and other advocates and, when appropriate, the individual who is mentally retarded". SB 2053, by forcing the closure of institutions, would substitute its decision-making process for that of the prescribed team.

We disagree with the assumption that SB 2053 will bring a more equitable distribution of DMH/DD dollars. Proponents of the bill state that 53% of DMH/DD moneys are expended on 13% of the developmentally disabled population. We do not question these figures, but we think it is important to note that the 13% are the segment of the developmentally disabled population - namely the severely and profoundly retarded - that requires the greater amount and kinds of care, and that this fact will not change whether they are served in the institution or the community. In fact, a greater expenditure of funds will be needed for intensive staffing

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and programming to prepare those developmentally disabled individuals who have serious behavioral and psychological problems for life in the community.

In conclusion, on behalf of the thousands of parents from the state of Illinois, we want to emphasize that we are not foes of community facilities, and we are not in favor of large institutions that have not been upgraded in accordance with the needs of the handicapped. We do not accept Senate Bill 2053's definition of an institution. We do believe in a developmental model of care in a least restrictive environment, and we strongly support the establishment of a full continuum of services required to meet the personal needs of all developmentally disabled people. We also maintain that both community-based facilities and the larger facilities each has its own role in contributing to that continuum. We strongly believe that all retarded people are entitled to all citizenship rights, and, in particular, to the freedom of choice of residential facilities which suit their particular needs.

Finally, please permit me to quote Senator Charles H. Percy (R-Illinois) who, after reading Senate Bill 2053, made the following public pronouncement:

> "For my part, I share the concerns of those who feel that the bill would unnecessarily eliminate excellent facilities in Illinois already providing quality care. Please be assured that I have no intention of either cosponsoring or supporting this bill."

CLIENTELE TO BE SERVED

BY PROGRAM CLASSIFICATION

	PROFOUND (IQ 0-19) Profound/Severe	SEVERE (IQ 20-34) Severe/Moderate	TRAINABLE (IQ 35-49) Moderate	EDUCABLE (IQ 50-69) Mild
HOUSING	SNF/MR	ICF/DD Group Home (CRA) SNF/MR	ICF/DD Group Home (CRA) CLF	CLF SLA
NATIONAL POPULATION	1.5%	3.5%	6%	89%
NEEDS: CHARACTERISTIC FUNCTIONING	Need Medical Model e.g.: Intravenous, toileting, bathing, are dependent 24 hours, ambulatory, non-ambulatory	Need Supervision a) Medication b) Toileting c) Hygiene d) Socialization e) Money concepts f) Ambulatory or non-ambulatory	Need Guidance a) Medication b) Money management c) Daily living skills d) Socialization and recreation e) Ambulatory or non-ambulatory	Need Support a) Money management b) Daily living skills c) Socialization and recreation Current needs met - limited volume
LEGAL STATUS	Declared incompetent. Full guardianship	Full or limited guardianship	Limited guardianship as needed	Full rights

EXHIBIT #1

EXHIBIT #2

NORTHWEST ROLLING MEADOWS
Monday, June 2, 1980 Section 1—5
THE DAILY HERALD

Clearbrook fight in center ring

by Thomas Quinlan
Herald staff writer

A clash that has been mounting since March over a proposed home for mentally retarded adults in a residential neighborhood of Rolling Meadows is expected to crest at a public hearing Tuesday night.

A five-member Special Zoning Commission created by Mayor William Ahrens will ask questions and entertain presentations before voting to make a recommendation to the city council, which eventually will decide whether to approve or disapprove the special request.

Members of the Concerned Citizens of Rolling Meadows fighting the proposed home and representatives from Clearbrook Center are expected to attend the meeting in full force.

Clearbrook, a non-profit organization in Rolling Meadows for handicapped and retarded persons, is seeking a special-use permit to built a two-story, 96-bed permanent care facility on a 3.5-acre site where its school is located. The $2 million facility is needed, Clearbrook officials contend, because there currently is a shortage of beds for handicapped adults needing permanent care.

BUT HOMEOWNERS IN the surrounding neighborhood are objecting to the size of the facility and the ordinance that would allow such a facility in a residential neighborhood.

Currently, the school at 3201 Campbell St. is used for a daytime training program for adults and an infant care program. Guerin Fischer, Clearbrook's director, has said the residents of the proposed home would be retarded adults who have single or multiple physical handicaps and are unable to live independently. Most would go to jobs in the suburbs during the day.

Residents protesting the facility have attended nearly every city council meeting since March, telling aldermen they fear for the safety of their children, the devaluation of their property and the aesthetics of the area.

"We don't mind the school at all," said one resident. "But all of a sudden they want to blow it up to an apartment building. That's what we object to."

Clearbrook and officials of the Suburban Townships Assn. for the Retarded, a group of parents with mentally retarded children, have said they've spent six years looking for a site before settling on Clearbrook's property.

DAN RUMOWSKI, a member of the homeowners' group, said the focus of the dispute has changed somewhat over the past few weeks.

"We're still challenging Clearbrook, but we're not attacking them anymore," he said. "We're fighting the zoning ordinance now."

The homeowners won one decision in the course of events when Clearbrook officials decided against seeking industrial/commercial zoning and will stay within its current residential zoning. But Clearbrook could still build the same facility if it receives a special use permit because its two-story plans would not violate any residential ordinances.

A neighborhood survey conducted in April by the homeowners' group showed more than 75 percent of those contacted against the plans for the home.

If the Special Zoning Commission comes to a decision Tuesday, the city council is likely to take the matter up for consideration at its next council meeting on June 10.

The public hearing begins at 8 p.m. in council chambers at the city hall, 3600 Kirchoff Rd.

CHARLES H. PERCY
ILLINOIS

CHICAGO OFFICE:
230 SOUTH DEARBORN STREET
CHICAGO, ILLINOIS 60604
(312) 353-4952

United States Senate

January 11, 1984

Ms. Mary E. Feldsien
Director of Development
Clearbrook Center Foundation
3201 West Campbell Street
Rolling Meadows, Illinois 60008

Dear Ms. Feldsien:

I would like very much to commend you and the staff and board of Clearbrook Center on the very fine job you are doing. Clearly your twenty-eight year record speaks for itself.

Clearbrook Center offers an invaluable service to the handicapped of all ages in the northwest suburban communities of Chicago. I am especially pleased to learn of the new residence facility you have planned. Facilities of this type accomplish a great deal in allowing their residents greater independence and access to a wide variety of community activities with far more opportunity to ultimately take their place in the work force. At the same time, the costs to the taxpayer are about half what they would be in a state institution.

I am also impressed by the fine grassroots support you have received from organizations and individuals within your community and the support you are receiving from many of the nation's top foundations. This is clearly a fine endorsement of your Center. I wish you continued success.

Sincerely,

Charles H. Percy

Charles H. Percy
United States Senator

CHP/eh

RECEIVED
JAN 13
CLEARBROOK CENTER

PHILIP M. CRANE
MEMBER OF CONGRESS
12TH DISTRICT OF ILLINOIS

WAYS AND MEANS
COMMITTEE

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HEALTH
SOCIAL SECURITY

Congress of the United States
House of Representatives
Washington, D.C. 20515

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ADMINISTRATIVE ASSISTANT

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Members of the 12th Congressional District

President Reagan and the members of Congress are highly encouraged by the business and voluntary commitment in the local areas for support of social service organizations. Clearbrook Center for the handicapped is currently serving 320 mentally retarded and physically impaired individuals in 13 different programs throughout the Northwest Suburbs of Chicago. Ground breaking ceremonies for Clearbrook Commons, a 90 bed intermediate care residential center for mentally retarded adults, was held in Rolling Meadows, Illinois during early September 1983, paving the way for a home that will keep our handicapped citizens in the community where they function best and bring others out of state institutions. It will operate under the concept of Normalization, the principle of helping developmentally disabled individuals obtain an existence as close as possible to the norms and patterns of society's mainstream.

Recent studies of the geographic area show a large demand for residential services for the developmentally disabled.

Clearbrook has already received 225 application requests for the 90 bed facility. The developmentally disabled adult in need of this service who is presently living at home, has aging relatives who at some point will not be able to care for his/her needs and would like a residential placement within the community.

Economically the mentally retarded can be cared for with greater quality and efficiency in the community. Nationally, efforts are under way to bring the mentally retarded citizens out of costly state institutions and back to their local areas where many more opportunities are available.

I wish to encourage and urge all of you to support the Clearbrook Commons project in any way possible, financially or as a volunteer, and to get to know this organization which has provided quality care for the handicapped for the past 28 years.Its growth and its progress depend on your assistance. Daniel Krause 12205 Roger Rd. Woodstock, Ill. 60098

Sincerely

Phil Crane

Philip M. Crane, M.C.
Illinois 12th Congressional District

VOICE OF THE RETARDED

798 LINDEN AVENUE
ELMHURST, IL 60126

Marty Pratt, *Chairman*
Phone: 358-8381
Jean Carlin, *Co-Chairman*
Phone: 474-4441
Bernadette Sullivan, *Secretary*
Phone: 834-2520
Liz Marguerite, *Treasurer*
Phone: 837-9481

ORGANIZATIONS ASSOCIATED WITH VOICE OF THE RETARDED

Little City Foundation	Palatine, Illinois
The Lambs	Libertyville, Illinois
Brother James Court	Springfield, Illinois
Clearbrook Center for the Handicapped	Rolling Meadows, Illinois
Dixon Association	Dixon, Illinois
Glenkirk Association	Northbrook, Illinois
Countryside Center	Barrington, Illinois
Good Shepherd Manor	Arlington Heights, Illinois
Happiday Center	Homewood, Illinois
Howe Center	Chicago, Illinois
Beverly Farms	Godfrey, Illinois
Ada McKinley	Chicago, Illinois
Kankakee Assn. for Mentally Retarded	Kankakee, Illinois
Lincoln Association	
Ludeman	
Meadows Association	Rolling Meadows, Illinois
Mount St. Joseph Association	Lake Zurich, Illinois
Misericordia Association	Chicago, Illinois
Murray Parents Association	Albers, Illinois
New Horizon Center	Chicago, Illinois
Parents Assn. for Handicapped Children	Hanover
Riverside Foundation	Mundelein, Illinois
St. Mary of Providence	Chicago, Illinois
Suburban Township for the Retarded	Mt. Prospect, Illinois
Waukegan Developmental Center	Waukegan, Illinois
Fox Center	Geneva, Illinois
Augustana Center	
Grove School	Evanston, Illinois

STATEMENT OF SISTER BARBARA EIRICH, DIRECTOR, COMMUNITY RESOURCE CENTER FOR THE DEVELOPMENTALLY DISABLED, INC., BRONX, N.Y.

Sister **Barbara**. Good afternoon.

I am the director of the Community Resource Center for the Developmentally Disabled in New York City. Our agency was formed in a direct response to the Willowbrook consent judgment which required, among other things, the development of least restrictive settings possible for individuals who were part of the class membership.

We presently are operating—or have operated up until today—four separate residences for individuals who have complex physical involvement and medical management needs. Today we are opening our fifth. We have opened the fourth and fifth house for persons who have been diagnosed and categorized as individuals, with high-risk problems for neuromotor, respiratory, and seizure disorders. These individuals had spent several years within a hospital setting. These folks have done very, very well within the community.

The first two houses we opened have individuals who came from the back wards, Senators, the back wards of institutions—individuals who were declared to be "profoundly retarded" or "severely retarded." Two of these young folks are right here—Marcus Pagan and Veronica Ward are with us this afternoon, evidence that there is great growth that can occur with folks if they are in a normal, natural setting and a small group setting. They have done exceptionally well, and so has the staff and the community itself.

Thank you.

Senator **Durenberger**. Thank you very much, Sister.

Mr. Brocato, and Sister Antoinette.

[Sister Barbara Eirich's prepared statement follows:]

TESTIMONY SUBMITTED TO
UNITED STATES SENATE COMMITTEE ON FINANCE
Subcommittee on Health
February 27, 1984
In Support of # S-2053

Submitted by:

Sr. Barbara Eirich

Sr. Barbara Eirich
Community Resource Center
for the
Developmentally Disabled, Inc.

SUMMARY OF MAJOR POINTS OF TESTIMONY
by Sr. Barbara Eirich before
UNITED STATES SENATE COMMITTEE OF FINANCE
Subcommittee on Health
February 27, 1984

MAJOR POINTS

1. Ownership as referred to in this testimony occurs at a fairly high frequency in small residential community based settings. Ownership in this concept has the following characteristics: closeness of relationships between staff and residents, and among the residents which is exhibited in the knowledge, respect, care, concern and interest in each other; an interest in maintaining the residence as neat, clean and homelike as possible; the possession, use and pride in ownership of personal possessions of the residents clothing, radios, pictures, etc.; a closeness of staff to resident to such an extent that an early detection of an illness or seizure is noticed in the slightest change in appearance or behavior; the staff demonstrate a sincere willingness to adopt policies and procedures that enhance the rights and safety of the residents; a general sense of advocacy for and an expectancy of development of each resident by the staff; and a sense of belonging in the community.

2. Individuals who have complex medical or medically related needs can live in small group settings in the community with appropriate supports.

3. Generic medical services have been and are available in the community for individuals predominently children, adolescents and young adults who have multiple handicapping conditions who are living in the community with their families.

4. Medical services are obtained more rapidly in small settings, as the staff are attuned to notice the slightest change in a resident. Since there are fewer persons in the setting, there is greater knowledge about each resident.

5. The quality and spectrum of medical services are better in the community. It is rare to hear of advocacy for medical service within an institutional setting.

6. Families would like to have their children/family members placed in small group settings near their own homes.

7. Community residential programs can be developed and monitored for quality of service with fewer regulations than the current Intermediate Care Facility for the Developmentally Disabled ICF/DD regulations.

8. Small residential settings for individuals with multiple medical management problems cost less than hospital care, and in many cases will cost less than the large congregate care institutions for the developmentally disabled.

9. Since physical integration is a pre-requisite to social integration, it is imperative that individuals who have special needs remain in the community to retain the level of integration.

The Community Resource Center for the Developmentally Disabled, Inc. is a private, not-for-profit organization formed to provide residential settings for individuals with complex medical or medically related problems associated with, or due to the effects of one or more developmental disability. The agency presently sponsors four separate residential settings in the South Bronx, and East Harlem areas of New York City. We are planning to open a fifth residence in late February, 1984. Each residence has been planned to provide home for a small group of persons in an effort to retain as much of a homelike atmosphere as possible. Four of the five residential settings have six residents, and one setting has ten residents.

I have been involved as Director with this particular service since its' inception in 1976. I have seen our residents change as they moved from large congregate care developmental centers and/or acute care general hospitals into the smaller homelike settings. We have been successful in retaining staff in each of the residences which we attribute to the fact that:there is ample opportunity in each day for each staff member to interact with our residents as family members; the staff are given on-going training to assist them to handle the needs of our residents; and last, but perhaps most important, is the fact that our staff and residents alike have an attitude of what I would call ownership within the small group setting.

The qualities that I use to define this ownership in the community are as follows: a respect for the dignity of each person regardless of his/her ability; a closeness of relationship between staff to residents and resident to resident that is exhibited in greater knowledge, respect, care, concern and interest in each other; an interest in maintaining the home as a home, and an effort to keep it neat and clean while it is being lived in, used and sometimes abused; an encouragement by the staff of the residents to obtain, retain and use personal possessions such as clothing, radios, clocks, watches, games, etc.; a closeness that produces a deep concern when one of the fellow residents or staff is ill or suffers from the death of a loved one; a closeness of staff to resident to such an extent that an early detection of an illness or seizure is noted by the slightest change in appearance or behavior; staff demonstrating a willingness to adopt policies and procedures that enhance the rights and safety of the residents, and will participate in the development of these policies and procedures should an accident or incident occur that had negatively affected a resident; a general sense of advocacy for the residents by the staff in obtaining medical care, education and day training services; an air of expectency that our residents will develop greater skills and socially acceptable behaviors; and there is a sense of belonging in the local community. I would venture to say that most of us learned these qualities from our own families in small settings. Most of us do not live with 20 - 40 - 50 - 100 or more persons as one single family unit. Larger congregate settings are not natural, and because of that fact, the qualities attributed to ownership as mentioned above, do not develop to the fullest potential in the larger settings. This statement does not mean that there is a lack of these qualities within the individual staff members within a large congregate setting. Ownership, as I perceive it, does not achieve full maturity within the large congregate care facility simply because of its unnatural size.

When I asked one of our residents what he thought would be important to tell people about the differences he found in his present home and Willowbrook State School, he said "the people here are nicer... the food tastes good..... I have my own clothes, radio and games..... I have friends..... I go to school (program)..... I like to talk to the neighbors.... I like it here...". This was shared by a young man who is now 23 years of age. When we picked this young man up at Willowbrook seven (7) years ago, he was diagnosed as functioning on a low level of severe mental retardation. His IQ score was 21. He presently demonstrates greater abilities than defined in 1976 within the institution. The psychologist in the institution noted in 1975 in this record, and in almost every record we received, the need for smaller, more homelike settings. There is no doubt that the Willowbrook Consent Judgment influenced the clinicians, but the message was clear - smaller group settings enhance development of relationships, and the development of people.

Perhaps the most significant fact that our agency can provide is that individuals who have complex medical management needs can live in small group settings in the local community outside a hospital or nursing home setting. Individuals who are physically handicapped and virtually dependent on others for all their daily living activities such as feeding, dressing, bathing, mobility, etc. not only can survive, but can thrive in a home whether it is located in a free standing house or in an apartment within a 50 - 1500 apartment complex.

The residents selected for our residential settings have complex medical or medically related needs. The staff need training to develop appropriate positioning, handling and feeding techniques to meet the needs of the residents so that these functions actually aid rather than inhibit the development of the resident. Each one of our residents have a multiplicity of medical or medically related diagnoses and needs which have been, for identification purposes, grouped together as follows: developmental - mental retardation (mild to profound retardation); physical disability (severe neuromotor involvement including scoliosis due to the effects of cerebral palsy); respiratory problems (including asthma); seizure disorders; gastrointestinal problems (including megacolon, esophogitis, gastrointestinal bleeding); sensory deficits (blindness, deafness); behavior management needs for socially unacceptable behaviors (including severe self abusive and self stimulatory behaviors); dental care; and nutritional needs (most of the residents are on special diets).

We have been successful in obtaining good primary and generic health care in the local community. These services have been available to the general public, and have been made more accessible and available to the developmentally disabled since the implementation of the Education Act of 1975. Many children who might have been placed in institutions for the mentally retarded due to the lack of educational and other support services prior to 1975, are still living at home with their families. They are currently receiving medical services in the local community. It is reasonable to expect that these services would continue to be available to individuals living in small group settings in the community.

During the past seven years, I have received over 100 referrals from families who heard of our program - most of the information was passed by word of mouth in the community. Without exception, the parents wanted their child placed geographically near them, in small group homes.

All of the programs sponsored by our agency are certified by the New York State Office of Mental Retardation and Developmental Disabilities, and are funded under the Title XX Medicaid Intermediate Care Facility for the Developmentally Disabled (ICF/DD) program. I believe that good quality residential programs can be provided and monitored by local authorities with fewer regulations. It is my belief that the Community and Family Life Amendment could enable the development of residential services with fewer regulations, at a lower cost than the institutional ICF/DD program

This past week I received a referral from a social worker at one of the city hospitals. The data and information was familiar. The recurring issue that boggles my mind is the fact that this particular child has spent twelve consecutive months within an acute care hospital - for lack of a home. The tax payers are paying over $600.00 a day for her care - a level of care she has not needed for the past 335 days. This child's needs could be handled by the family with sufficient support, or by a group residence. It is inexcusable to allow such a waste to occur of the public resources. Here again, the acceptance and approval of the Community and Family Living Amendments of 1983 S-2053 would enable the development of appropriate services at a fraction of the current hospital costs.

It should be noted that we took six individuals from Flower Hospital in 1980 and placed them in the small residential setting. The hospital per diem at that time was over $300.00, while we received approximately one half that amount. We will be admitting six more individuals into a new residence the week of February 27, 1984. The hospital is now receiving over $350.00 a day per client. We anticipate receiving approximately one half that amount.

In sum, I would personally like to see the Community and Family Life Amendments S-2053 moved forward for approval in Congress. It is an amendment for families, for the continued development of people who happen to have very special needs.

STATEMENT OF SISTER MARY ANTOINETTE BARONCINI, ADMINISTRATOR OF ST. MARY'S TRAINING SCHOOL FOR RETARDED CHILDREN, ALEXANDRIA, LA., ACCOMPANIED BY DR. MAURICE DAYAN, MS. MATHILDE BRADFORD, AND THOMAS BROCATO

Sister Antoinette. Mr. Chairman, I am Sister Mary Antoinette Baroncini, administrator of St. Mary's Training School, a private nonprofit intermediate-care facility for mentally retarded located in Alexandria, La. I am here representing the views of our diocese and Bishop Charles P. Greco, founder of St. Mary's and Holy Angels Training Schools.

I have with me Dr. Maurice Dayan, our consultant psychologist, Ms. Mathilde Bradford, our director of social services, and Mr. Thomas Brocato, our legal counsel. At this time I would like to call on Mr. Brocato to speak in our behalf.

Mr. Brocato. Mr. Chairman, I am Thomas K. Brocato, counsel for St. Mary's Training School and a member of Governor-elect Edwin Edwards' Select Advisory Committee on Mental Retardation in the State of Louisiana, and I represent his views in this regard.

Some 30 years ago in the State of Louisiana the need for residential care of the mentally retarded became a primary concern of many of the members of our community, and most notably then-Bishop Charles Greco, who, as the result of his concern, recruited the congregation of Our Lady of Sorrows from Italy and brought them to America to provide this care.

We did not have funding of any sort other than donations and some grants at that time.

Now, we have several oppositions to this bill, the first being that we are opposed to the notion that an en masse predetermination is going to be made that all mentally retarded clients will be placed into the community regardless of their degree of retardation and without a professional determination of whether or not such is appropriate.

We have had instances, and experience has taught us in the past, that there is recidivism, there are abuses which occur, and that these can be minimized, and that in some cases institutional care is better for some individuals than not.

In our view the bill does not or will not result in a saving of money for the Federal Government, because our understanding of it is that the numbers of persons who are presently in the community who are retarded but who cannot get Federal funds will be able to come in under this bill and be funded in community settings.

We also would like to point out that not all institutions such as the institutions which were used for the studies to show that severely and profoundly retarded could prosper in a community setting—the facilities that they came from previously were not of the caliber that ours is and were not of the caliber that exists in the States presently. There was a different situation in those previous years.

We are not opposed to community living as an option; we support a full array of services. We want to make that point very clear. We think that the community home has definitely has a place in the care and treatment of the mentally retarded in this Nation. However, we are definitely opposed to the lack of choice, freedom of choice, for the families of the retarded individuals and of the professional input to make those choices as to the appropriate setting.

For these reasons, we would ask that the bill be unfavorably reported.

Senator DURENBERGER. Thank you very much. We let you go a little longer because Senator Long just couldn't be here; he was tied up somewhere else. Half the State of Louisiana must be here, so he regretted not being able to come down.

Mr. BROCATO. Thank you, Senator.

[Mr. Brocato's and Sister Mary Antoinette Baroncini's prepared statement follows:]

ST. MARY'S TRAINING SCHOOL STATEMENT OF OPPOSITION TO SENATE BILL #2053

BY THOMAS K. BROCATO, ATTORNEY

FEBRUARY 27, 1984

I am Thomas K. Brocato, legal counsel for St. Mary's Training School, a private, non-profit, intermediate care facility for the mentally retarded, located in Alexandria, Louisiana. I am also a member of Governor Elect Edwin Edwards select advisory committee on mental retardation in the State of Louisiana. With me is Sr. M. Antoinette Baroncini, Administrator of St. Mary's, Mathilde Bradford, Director of Social Services at St. Mary's, and Dr. Maurice Dayan, Consulting Psychologist for St. Mary's.

We appear before the Committee to voice our opposition, and the opposition of the incoming Administration of the State of Louisiana, to Senate Bill #2053, by Senator Chafee. I have specifically been authorized by Governor Elect Edwards to speak in this regard.

The effect of this measure, if enacted into law, will be the extinction, within 10 to 15 years, of all intermediate care facilities having a capacity of more than fifteen. Institutionalization will no longer exist as a residential living option for any person, no matter how profoundly retarded or disabled. This must not happen.

We are not opposed to the community living concept as an option for the mentally retarded, and we commend the Senator's efforts to devise a federal funding mechanism specifically for the "group home" concept. However, elimination of the institutionalization option will visit an incalculable harm on the entire mental retardation community of this nation; and more importantly, will forever cheat those mentally retarded citizens who best prosper in an institutional setting, of their inalienable right to realize their fullest potential and happiness. Likewise, the families of these citizens will forever be cheated of the peace of mind that when they are gone, their special child will be cared for in an institution of proven stability, longevity and quality.

Finally, assuming that one decade hence, society is inundated with retarded citizens for whom community placement is inappropriate, abuses of the most heinous sort will befall these persons. The societal cost of dealing with these abuses and the expenditure of community resources to address and eliminate them will make the cost of institutionalization seem a bargain, in terms of both money and humanity. However, the bargain will no longer be available, because the institutions will no longer exist.

Our facility, and all other public and private facilities of our state maintain a "least restrictive environment" concept, in accordance with the Title XIX philosophy. Many of us have for years advocated and implemented a program for community placement, on a voluntary basis, where appropriate. However, much careful thought, planning and review is spent in making a determination of whether a community placement is appropriate.

Senate Bill #2053 eliminates individual consideration of each case, and instead, makes an En Masse legislative predermination, which in many cases will adversely affect the purported beneficiary, his or her family, and society in general. For these reasons, and for the reasons to be more fully discussed by my associates, we are opposed to Senate Bill #2053 and ask that it not be favorably reported.

ST. MARY'S TRAINING SCHOOL STATEMENT OF OPPOSITION TO SENATE BILL #2053

BY MAURICE DAYAN, Ed. D., CONSULTING PSYCHOLOGIST

FEBRUARY 27, 1984

I am Dr. Maurice Dayan, consulting psychologist for St. Mary's and Holy Angels. I have almost thirty years experience in mental retardation and provide psychological services to community homes as well as residential facilities.

I would like to give some factual reasons why we are opposed to Senate Bill #2053 as written.

1. First of all, historically, only 3-4% of the mentally retarded have needed and have been served by residential programs and need Title XIX ICF funding. Senate Bill #2053 as presently written would open the door and develop dependence on the Federal dollar for a large number of the 96% who previously have not been served. Title XIX ICF-MR would no longer be a "most in need"-"last resort" funding program.
2. With the improvement of medical care, the numbers of severely and profoundly retarded are increasing because of an increase in their life survival rate. As a result there are a larger number of medical-at-risk individuals who need constant medical care and supervision. This medical care is not presently readily available in the community and an increasing number of physicians are refusing to accept Medicaid patients in the community.
3. There presently is a dire shortage of professionals trained in working with the mentally retarded. The dispersal of the small 3% of the mentally retarded from the institutions will bring about dispersal of our professionals who will be spending more time traveling than providing professional services.

4. Senate Bill #2053 advocates the "Big is Bad/Small is Good" position. Research studies suggest this is a gross oversimplification. Technical information including review of the literature can be provided to the Committee upon their request.
5. Another assumption underlying Senate Bill #2053 seems to be that life in an institution is bleak and sterile and that life in the community will be more enriching and satisfying. A review of the literature clearly indicates that for retarded individuals, life in the community is not all that it purports to be. While we can force physical integration of retarded individuals, we cannot mandate community acceptance.
6. Senate Bill #2053 implies that institutional care is far more costly than placement in a community based residence. When more accurately compared (Community Services/Room and Board versus Institutional Placement/Full Aray of Services), community placement is not less costly than institutionalization.
7. Senate Bill #2053 takes away the freedom of choice for the parents and families of the mentally retarded. As parents get older, they are concerned with the ongoing security and care for their children in the inevitable event of the parents death. Community homes have yet to prove stability and viability.

There are many other valid points that can be made in opposition to the bill if time were allotted. I sincerely hope that all ramifications of this legislation be considered before a judgment is rendered upon residential facilities.

ST. MARY'S TRAINING SCHOOL STATEMENT OF OPPOSITION TO SENATE BILL #2053

BY MATHILDE BRADFORD, DIRECTOR OF SOCIAL SERVICES

FEBRUARY 27, 1984

I am Mathilde Bradford, Director of Social Services at St. Mary's School for Retarded Children, and would like to speak in opposition to the Chafee Bill for several reasons. First, through phasing out residential care, this bill will deprive parents and professionals of the option to use this type of care if it is felt most appropriate for a particular child or retarded person. We need an array of services for the mentally retarded including both community based care and residential care. Parents and professionals should have quality residential care as an option to consider in working out the most appropriate plans for the retarded. This type of care has already proven itself to be both valuable and effective. Under the provisions of Title XIX (431.51) parents and clients have the right to chose and obtain services from any qualified Medicaid provider but if residential care is phased out, they will be deprived of their right to freedom of choice in regard to securing residential care for their loved ones.

It would indeed be tragic if one type of care, i.e., community based care, is overemphasized at the expense of residential care to the point that residential care would disappear and no longer be a viable resource for consideration in making appropriate individual care plans. Should this happen and residential care and institutions are lost, they will be lost forever and will not come back for the amount of money needed to reestablish such facilities is not likely to be forthcoming in the future. We will be throwing out the baby with the bath if we dispose of residential facilities. Quality care can be given to the mentally retarded in a number of ways and quality, individualized residential care is one of these ways. It has been said that a rose is a rose is a rose, but we cannot say that a child is a child is a child. Children have different, varying needs depending upon their particular capacities and we must continue to be able to utilize an option of residential care when this seems indicated as most appropriate. We must have a variety of resources to meet a variety of needs and quality residential care is certainly one of the options which we must continue to keep.

Section 1, Page 26 Sunday, January 22, 1984

The Times-Picayune

Issued every Sunday by The Times-Picayune Publishi

YOUR OPINIONS

LETTERS

Helping the retarded

Metairie

I am the mother of a severely retarded child

Fortunately, my son Kevin is receiving excellent care and professional training and guidance at the St. Mary's Training School for Retarded Children in Alexandria.

It is always a pleasure for me to visit my son at this wonderful institution and to meet with the dedicated and competent teachers and assistants who do such a marvelous job with the children.

Sen. John Chafee has introduced in Congress Senate Bill 2053 entitled "Community and Family Living Amendments Act." If this act passes, Medicare funds will be diverted from such institutions as St. Mary's and be given instead to small, family-size community living arrangements.

I believe the decision on what is best for each retarded child should not be determined by a legislative act, but should be made by professionals in the field of mental retardation and the parents or guardians of the mentally retarded individuals.

We don't need laws that would withhold funds from facilities such as St. Mary's when experience has proven that for the majority of retarded children within the classifications being cared for at St. Mary's the expert care and professional help these unfortunate children are receiving cannot possibly be equaled by the type of care being suggested by Sen. Chafee.

For example, the autistic children at St. Mary's can be helped only by professionals with the technical skills required to help such children reach their potential. Such children would be lost in the kind of community being suggested by Sen. Chafee.

I would suggest to Sen. Chafee and to Sen. Dave Durenberger, chairman of the subcommittee on health, that they visit St. Mary's Training School in Alexandria and see for themselves the loving and professional care that these little retarded citizens are receiving. Then I am sure they will no longer advocate the passage of the act at issue, which will eventually lead to the demise of St. Mary's Training School for Retarded Children.

Catherine A. Comeaux

Town Talk, Alexandria-Pineville, La., Monday, January 16, 1984 D-3

Conditions in Calif. Facilities Called 'Abusive'

N.Y. Times News Service

SACRAMENTO, Calif. -- A state com- ssion, reporting on a nine-month inquiry, s found "abusive, unhealthful, unsafe and caring conditions" in California com- nity care facilities that house the eld- y, the mentally ill and the physically dis- ed.

The report by the Commission on Cali- nia State Government Organization and onomy calls the 150,000 adults and chil- en in the state's 22,000 licensed com- nity care homes "California's defense- s citizens."

Community care facilities are different m nursing homes in California, which use more residents, are mostly for the erly and are more closely regulated. Of the 22,000 community care facilities, 18,000 are licensed for six or fewer residents, the report said.

On Thursday, Nathan Shapell, the commission chairman, announced the findings of visits to some of the 22,000 facilities, saying, "Some residents are actually killed in facilities each year."

"We found that daily, throughout this state, residents of community care facilities are being sexually abused, beaten, fed spoiled food, forced to live with toilets that don't work, left unattended and generally subjected to a demeaning existence," he said.

The State Department of Social Services is to prepare an analysis of the report. A department official said: "These type of facilities experience the same problems as they do in other states. We view the report as not so critical of what we are doing but what some types of changes that could be done by the Legislature."

State Assemblyman Tom Bates, Democrat of Oakland, chairman of the Assembly's Committee on Human Services, and state Sen. Henry Mello, Democrat of Waterville, chairman of the Senate Subcommittee on Aging, said they planned hearings on possible legislative proposals.

Shapell, who is chairman of the board of Shapell Industries and Construction, told of a facility in southern California whose bedridden residents were found lying in their own excrement and of a Napa County facility operator who forced a resident to have sexual relations with him.

Shapell said, "We recognize, of course, that many facilities provide very good care to residents who in many cases are extremely difficult to handle."

The report quotes a representative of the community care industry as saying, "The conditions are far more severe than ever existed in nursing homes 15 years ago — it's a snake pit out there."

"California government is faced with an enormous task in overseeing community care," said Jean Kindy Walker of Modesto, a commission leader. "Although our report only addresses the elderly, the developmentally disabled and the mentally disabled, foster children and substance abusers are also parts of this system."

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YOUR OPINIONS

LETTERS

Retarded need help

New Orleans

First I wish to commend you for printing the letter from Catherine A. Comeaux on helping the retarded (Letters, Jan. 22).

I, too, am the mother of a retarded son who has been a resident of Pinecrest State School in Pineville for 20 years. Under the professional help of a dedicated, well trained staff, he has made a tremendous improvement that would not have been possible if he were not there. His life has been so much happier and satisfying because of the training he is receiving there.

I am greatly disturbed by the introduction of Senate Bill 2053, entitled Community and Family Living Amendment Act. If this bill should pass, Medicare funds will be divested from such institutions as Pinecrest. This would mean a great loss and a big cutback on services currently offered and much needed.

Legislators who have little or no knowledge of the type of services needed for our retarded citizens are, in my opinion, in no way equipped to make decisions that should be made by professionals in the field of mental retardation and the families and guardians of the retarded individuals.

Many of the residents at Pinecrest would be totally lost in an environment suggested by Sen. Chafee. I have written to Sens. Johnston and Long. Both have promised whatever help will be possible.

I would suggest that all legislators, both national, state and local, take time out of their busy schedules to visit such institutions as Pinecrest or St. Mary's Training School for Retarded Children in Alexandria and see first-hand the wonderful services these retarded citizens are receiving.

Veronica B. Hill

ST. MARY'S TRAINING SCHOOL STATEMENT OF OPPOSITION TO SENATE BILL #2053

BY SR. M. ANTOINETTE BARONCINI, ADMINISTRATOR
FEBRUARY 27, 1984

I am Sister Mary Antoinette Baroncini, Administrator of St. Mary's Training School, a private, non-profit intermediate care facility for the mentally retarded located in Alexandria, Louisiana.

I am here representing the views of our Diocese, and Bishop Charles P. Greco, founder of St. Mary's and Holy Angels Training Schools. I have with me Dr. Maurice Dayan, our consultant psychologist, Ms. Mathilde Bradford, our Director of Social Services, and Mr. Thomas Brocato, our Legal Counsel. At this time, I would like to call on Mr. Brocato to speak in my behalf.

ST. MARY'S TRAINING SCHOOL STATEMENT OF OPPOSITION TO SENATE BILL #2053
BY THOMAS K. BROCATO, ATTORNEY
FEBRUARY 27, 1984

I am Thomas K. Brocato, counsel for St. Mary's Training School. I am also a member of Governor Elect Edwin Edwards select advisory committee on mental retardation in the State of Louisiana, and I have been specifically authorized by the Governor elect to represent the views of the incoming administration on this bill. We oppose this legislation, for the following reasons. As a result of this bill, residential living in larger institutional facilities will no longer exist as an option for the mentally retarded. Community living options, or "group homes" will be legislatively pre-determined as appropriate placement for all mentally retarded citizens, regardless of the degree of retardation or other disability, and without considered professional and familial judgment of whether such placement is appropriate for the individual. Experience has taught us that in many cases, even after considered judgment is exercised, community placement proves to be inappropriate, and often detrimental to the well being of the client. Assuming that one decade hence, society is inundated with retarded citizens for whom community placement is inappropriate, abuses of the most heinous sort will befall. The societal cost of dealing with these abuses and the expenditure of community resources to address and eliminate them will make the cost of institutionalization seem a bargain, in terms of both money and humanity. This bill has been represented as a money saver; however, historically, only a very small percentage of the mentally retarded have been served in institutional settings. Rather than decrease dependence on Federal funding, this bill will open the way for many individuals not previously obtaining Title XIX support to do so. The program will no longer support only those for whom it was originally intended; that is, those most in need. In order to truly evaluate the fiscal impact of the measure, one must consider that institutional care includes many services, which in a group home setting must be purchased in the community, such as medical care, speech therapy, and physical therapy. Proper care and treatment of the mentally retarded is not accomplished by merely providing room, board, and supervision. Many of the services required are not readily available in the community. Decentralization of these services can only be more costly and less efficient. The bill assumes that all mentally retarded citizens will reach their highest potential only in a community setting. However, studies which appear to support this notion should be viewed cautiously. Many variables must be considered in determining the validity of these studies, such as the degree of retardation of the individuals involved as well as the quality of staffing and programming of the individual's previous institutional placement. Life in a modern quality facility such as ours is not a bleak and sterile existence. Progress in normalization and developmental model is achieved. We are not opposed to the community living concept as a valuable and needed option for the mentally retarded, and we commend the Senator's efforts to devise a Federal funding mechanism specifically for the "group home". However, institutions should not be eliminated simply because community living is a valuable option. There is, and always will be a need for both. Extinction of institutions will visit an incalculable harm on the entire mental retardation community of this nation which has spent many hours and dollars in developing quality programs and facilities for the care of the mentally retarded. It will deprive those mentally retarded citizens who best prosper in an institutional setting, of their inalienable right to realize their fullest potential and happiness. Likewise, the families of these citizens will forever be deprived of the peace of mind that when they are gone, their special child, or loved one, will be cared for in an institution of their choosing, with proven stability, longevity and quality. Many of us have for years advocated and implemented a program for community placement, on a voluntary basis, where appropriate. However, much careful thought, planning and review is spent in making a determination of whether a community placement is appropriate. Senate Bill #2053 eliminates individual consideration of each case, and instead, makes an En Masse legislative pre-determination, which in many cases will adversely affect the purported beneficiary, his or her family, and society in general. For these reasons, and for the reasons to be more fully discussed by my associates, we are opposed to Senate Bill #2053 and ask that it not be favorably reported.

Senator DURENBERGER. John.

Senator CHAFEE. Thank you, Mr. Chairman.

Sister Barbara, I would like to ask you a question. As I understood your statement, you now have some five homes, as of today. How many in each home?

Sister BARBARA. We basically have six young people in each residence. We have residence that has 10 young people.

Senator CHAFEE. And you said that these young people are in some instances severely physically disabled as well as mentally retarded?

Sister BARBARA. Yes, sir. Three of the houses that we have opened have individuals who are functioning on the profound level of retardation. They have severe physical deficits. They are basically a nonambulant group of persons. They have multiple contractures of all of their extremities, severe scoliosis, and very complex medical problems. Some of these individuals are at high risk for seizures and respiratory problems.

Senator CHAFEE. Now, are you able to handle these individuals in this small setting?

Sister BARBARA. Yes, sir.

Senator CHAFEE. Give me your thoughts on your ability to care for these individuals in small settings.

Sister BARBARA. I think that part of the issue at hand for us is to look at the needs of the particular individuals that we are serving, and staff accordingly, and train our staff so that they have the skills with which to handle the needs of the population.

I think that one of the factors that we realized happened when we opened up a residence for 10 young people, was that it was very difficult to manage the situation. And the reason is that each person has anywhere from 50 to 100 management needs, and it is very difficult for the staff to relate to that. When you drop the residential population down to a smaller number of persons, there is a great closeness that comes, an awareness of need that emerges by the slightest change, a change in the way that the person looks, gives eye contact or doesn't give eye contact, or moves or does not move. We were able to identify indicators for immediate medical attention. It may be the way that a person moves that indicates that a seizure is imminent and that care needs to be provided instantly.

We have found that the larger the number of management issues, the resident population presents, the smaller the number of persons in care should be.

Senator CHAFEE. Now, it has been my experience, and obviously I haven't had half the experience that any of these witnesses or that many of those gathered here today have had, but it has been my experience in observing those in a small unit that the growth of the person toward realizing his or her potential seems far greater than in an institution. Am I correct in that, from your greater experience?

Sister BARBARA. In my experience, Senator, that has been the case. Part of the reason is due to the fact that individuals who have complex management needs, tend to trigger reactions and behaviors in other residents. Another fact is the nature of impact on the staff person. For example, a staff person entering a residential setting serving 20 to 30 persons, each having 30 to 50 individual needs and deficits, perceives the magnitude in a geometric proportion. The impact provides the staff person with the perception that little can be done for each resident because the staff person sees several hundred needs, which is an overwhelming experience. In the smaller setting the staff person is in a position to identify at least 10 or 20 prioritized needs in each individual that could be effectively managed during a 24-hour period. The smaller setting is more normalized and allows for greater knowledge of each resident. Results of programing is seen almost immediately. The staff can increase development rather than inhibit it, just by the way they handle, feed, transfer, and assist a developmentally disabled person in programing. Since the smaller setting is more home-like, the staff have a healthier self-image of themselves and have a greater expectancy of response in each resident. This element of expectancy in learning is what has helped us all grow. Studies conducted on the children attending inner-city schools in the 1960's clearly indicated that the students whose teacher expected them to learn, actually did learn. Individuals who have one or more form of developmental disabilities need to be perceived as persons who can and do learn. Smaller settings can enhance the learning process.

Senator CHAFEE. Well, thank you, Sister.

Sister BARBARA. You are welcome, Senator.

Senator CHAFEE. And I just want to pay tribute to the work that you have done, as well as that of the other witnesses here. I appreciate it.

Senator DURENBERGER. Senator Dole.

Senator DOLE. I wanted to ask Ms. Shreve how S. 2053 would directly affect your operation.

Ms. SHREVE. My operation, per se, I'm not sure. In terms of what we might be able to help others do who are living in the community, a great deal.

I probably need to clarify that. The Whole Person has a policy of not being the primary service provider if at all possible; in other words, we are trying to work with community resources to make sure they are in place. Therefore, we would not particularly want to be a vendor or be a provider of medicaid service if there is another agency in the Kansas City area that could provide that to our population.

Our biggest problem right now is that those services don't exist, or if they do they are so restrictive that the only alternative becomes nursing home care. And for our population especially, medically stable individuals, this does not seem to be appropriate, and it seems to be far more expensive.

Senator DURENBERGER. Well, as I understand—let's see—we have three witnesses opposed to S. 2053? Or less?

Senator CHAFEE. Three.

Senator DURENBERGER. Have you had an opportunity to see whether you might be able to modify S. 2053 and therefore remove your opposition or soften your opposition?

Mr. DECKER. Senator, we are not against deinstitutionalization, and we would support the concept in that we are not opposed to seeing a decrease in the numbers of people within larger institutions to smaller facilities, if in fact that is appropriate for their care.

I think one of the basic problems that most everyone has is the timeframes and the phasing out, and mandating that there is only one modality that you can utilize.

Mr. **Fischer**. I would like to add, if possible, that on exhibit 1 of my presentation, Senator Dole, if there was a configuration of services that would handle everyone from profound in the right setting, with the right kind of model, the right kind of people to take care of their needs and functions, and also if there was a legally associated status of that individual from profound all the way to educable, or "mild," if you want to use that term, that would show a continuum of services that I think the organization that I am representing would buy as far as S. 2053.

As it is written right now, these needs of the important people from zero to 19 IQ up to higher is not being met, and we feel it is very important that there has to be the basic issue of nonlumping of all of them into one configuration of service, which as originally written is less than 10, whether it is a State institution or whether it is community.

Mr. **Brocato**. Senator, if I could defer that question to my colleague Dr. Dayan, who is a clinical psychologist.

Dr. **Dayan**. Thank you. There are several alternatives, and of course one of the alternatives is the alternative that the National Association of State Program Directors is presenting and looking at as an alternative. It's a viable concern.

I think there are a couple of things we are concerned about: We have not opposed community programs. In fact, we would like to look at a funding mechanism that will strengthen and give a little more support to those masses of numbers of people who have utilized volunteered dollars. We haven't even talked about all of those volunteers dollars that had gone into programs before there was a medicaid.

We can go across the country and look at programs all over the country that medicaid has not even supported that are excellent programs—in Houston, Tex.; in St. Petersburg in Florida—where the percentage of dollars is all local dollars, volunteer dollars.

What we are talking about is leaving a way so that all the various alternatives and all the choices are there for the citizens of the communities and the parents of these handicapped individuals can make those choices.

Basically, what the basic alternative is, as I see it, would be to first of all say, "Let's look at the most in-need group, 3 to 4 percent of the mentally retarded, and find the funding mechanisms through medicaid, and then for those 96 percent who are not most in need, find some lesser restricted combination of contributions of the community toward that funding; for example, matching Federal dollars with United Way dollars earmarked for community services." If not, we are going to have a massive amount of people trying to get in on the dollars available which is going to decrease the number of dollars in the country per client.

Senator **Durenberger**. Thank you very much.

I want to make just one brief statement, and perhaps in the form of a question, that follows this line of questioning.

Just as other members of this committee, the thing that is bothering me is that I would like to find some mechanism by which I can facilitate choice in the system by someone other than me. So if anybody has any great ideas on how to do this, please bring those ideas up here with you when you testify.

In everything we have heard here today it seems to me that the States—Rhode Island, and a bunch of other States—have been out ahead of everybody generally, certainly ahead of us at the Federal level, in moving in the direction of a more sensitive individualized approach to this problem.

Now it looks like we have a shift here, where we are coming to the Federal Government, because apparently nobody has adequate resources, and asking for, basically, a mandated Federal program to do certain things. It bothers me that that appears to take some of the choice and some of the decisionmaking away from the local level.

I would like you to react to that, particularly those of you who are in favor of this bill.

The second part of that question is this problem of what we sometimes call "substitution," when we do long-term care and then we do intermediate care and then we do the SNF's and then we do home-health, and we do this kind of home health and that kind of home health, with all the mandates. And we never save any money, or we never raise the level of care.

There are some figures in the Congressional Research Report on S. 2053, that says that right now there are 138,738 persons who received ICF/MR services in 1982. But, "estimates of eligible persons range from 725,000 to 2 million."

Now, it would seem—and maybe this is John's idea and he should be saluted for it, but I don't know who those 2 million people are—and the closer you can get to the Bronx model, the more of these 2 million people you are going to serve. Are those people today unserved where they are? What is going to happen with regard to those 2 million people?

Sister Barbara?

Sister **Barbara Eirich**. Sir, I would just like to make a statement that there is a group of individuals who are within a hospital setting at the present time. Today we are taking the seventh person out of a hospital setting at over $350 a day.

Senator **Durenberger**. So, some of those are in very expensive settings, paid for out of some other funds?

Sister **Barbara Eirich**. That is correct; and I have a recent referral that just came in last week for an individual who is in care in a city hospital at over $600 a day, and that level of care is not needed.

So, in some instances individuals are within the hospital health care system somewhere.

Senator **Durenberger**. Where are the rest of them? Are they at home, a lot of them, particularly the young?

Sister **Barbara Eirich**. There are a large number of persons who are at home at this point in time, but I am looking at the persons who are more physically involved, have a need of a lot of support services, and in a sense removing them from a hospital setting reduces dramatically the cost of care on a per-diem basis.

Mr FISCHER. Senator, there was a study done recently in Illinois that indicates that there are over 8,000 people of that group that you alluded that are not receiving medicaid funds now, that are at home with their elderly parents, that are going to have to be someday funnelled into the system.

Right now we are in the process of completing a 90-bed facility, which I talked about, totally raised locally by corporations and parents and foundations, and with a waiting list of over 300 in the community, not even counting the people that we would like to take if they are appropriate from State institutions, like we have done in the past to our group homes. So that is where a good share of them are, if you just number that out through the country. There are a significant amount of people who are not receiving it but who will someday, when they can't stay home any longer.

Senator DURENBERGER. Margaret.

Ms. SHREVE. I was going to suggest that at least for my population we have found that oftentimes there are many informal support systems in place in the community, and I don't think that this bill is necessarily going to change that.

But what happens is, if the informal support system breaks down, then the person is "at-risk," OK? If there are no other alternatives, if there is no way to get some in-home services in place to keep that informal system going, that's when you are going to run into a major cost factor.

For our population, there are a lot of people who are living in the community now with very little help, but they also tend to incur higher medical bills when they do need help.

Senator DURENBERGER. Well, what, besides a lot of TLC, are supporting this population that is not in an institutional setting?

Ms. SHREVE. Well, in Kansas City, for example, what we tend to utilize most heavily is a section 8 subsidized housing unit to try to get somebody into an accessible apartment.

We have a city sales tax that supports our transportation system, so people are mobile. We have a degree of medicaid and sometimes medicare services available through home health agencies, which we will use as much as we can.

The educational opportunities are there. If a person has a vocational goal or potential, then they are usually a client of vocational rehabilitation in each State.

In other words, we have such a massive bureaucratic system that we can work through, if we can train—well, in our case we are training consumers to work through it, not providing the services ourselves.

There are bits and pieces available, but the major piece that we see missing tends to be the hands-on help, it tends to be the service that is provided by medicaid if you are willing to go to an institution.

And in our case, we have been saying, "Look, if that's the only option we have had for so long, I don't see anything wrong with changing the option and saying, 'If you want to go to an institution, you are going to have to find sources other than Medicaid to pay for that.' "

Senator DURENBERGER. Are there any other comments on the issues of the mandates and choice and substitution and costs?

Dr. **Dayan**. Well, first of all, I would like to make one statement: Institutions don't go out and recruit clients; clients come to institutions because the community has not provided appropriate services to them. And historically, if you look at the admissions policies of the majority of the facilities in the last 10 or 15 years, they have been facilities of last resort, because communities have not provided those services.

So, institutions don't want the clients, they want the clients served.

The other factor is, development of an individual doesn't take place based on whether it is an institution or large or small, it is in the quality of care of the program. I think the important thing is how the funding mechanism provides a quality program, wherever it is provided.

Senator **Durenberger**. I guess Sister Antoinette was going to add something.

Sister **Antoinette Baroncinė**. I would like to tell Senator Chafee that we don't like to call St. Mary's an "institution." St. Mary's is a home. It is individualized for each child, and, like Bishop Greco said, we feel that nothing is too good for these children. And that is the way we treat our children.

We have all services for them; they are free to go out; they take part in sports, and everything.

Our "institution," if you want to call it that, has just 150 beds, and we want to keep it at that number. We don't want to get any larger.

So I do think that we need some group homes even though we have had a sad experience with group homes; in fact, one of my boys right now is walking the street in Baton Rouge, and he is a male prostitute. This is the result of a group home without planning and adequate supervision.

But I agree with Sister in that that was an exception. It is not to compare with St. Mary's, or Holy Angels or other institutions. Those two reports here are great, and I agree with them, but those are the exceptions. You cannot compare them with the regular facility.

And for my last statement, I would like to invite Dr. Carl to come to see St. Mary's.

Senator **Chafee**. Fine.

It seems to me, if I could summarize the views of those who are opposed, that it isn't that they are opposed to group homes; what they are opposed to is the lack of choice, as it were, the lack of—there is a code word for it, what is it?

Mr. **Fischer**. Alternatives?

Senator **Chafee**. Well, OK, "alternatives." It is more complicated than that. I could have gotten that one, I think. [Laughter.]

Senator **Chafee**. But here is the problem that we face: The States say, "We are not opposed to the group homes, but we don't think everybody should be in a group home, and we should have"—if I could use the word—"a State 'institution.' "

But the fact of the matter is, the States aren't moving in that direction. And, as Ms. Shreve says, the facilities aren't there in the community.

So when the home care system breaks down, the mother or father who is taking care of the retarded child dies or gets terribly sick herself, there is no alternative but to go to the institution. There isn't an alternative in most of the States.

So, whereas everybody pays lipservice to the issue of a continuum of care—I don't mean the people here pay lipservice, but I mean the State legislatures and the Governors, and so forth—they say they are for community-based services, but the dollars continue pour into the institutions.

I imagine if you compared the capital expenditures for institutions versus group homes across the Nation, it would be no comparison at all; it must be 10 to 1. You can get a bond issue passed for institutions for the mentally retarded, but nobody thinks of doing it for the group homes.

So here we are. We believe, at least I believe, that the better care comes—not in every instance, but in most instances—from the smaller units, as Sr. Barbara spoke of.

Now, how do we get a slant in that direction? We are not getting anywhere the way we are going now. What we have is control over certain funds, they are Federal funds. We don't have control over all funds. I think in the figures that came through, Federal medicaid dollars amount to about 50 percent. Wasn't that what the first witness said? Dr. Braddock indicated about 50-50.

So what we are saying, or what this legislation is saying, is that we are going to direct more of those funds toward the group homes. Absent that kind of incentive, nothing positive is going to happen across the country; at least, that is what history has proven so far.

Now, what is the answer to that, Mr. Decker? Why shouldn't we do this? We don't see much happening as far as these group homes go across the Nation.

Mr. **Decker**. First of all, Senator, I think that if you will take a look at the information—I think it is in Dr. Braddock's study, and if it isn't I believe it is in the study that has been done by Richard Schoenberger—it indicates that since 1974 there has been a tremendous increase in the number of group homes across the United States. And it has been during that period of time that we have seen a real expansion in those homes.

The information that was given to you by Dr. Braddock shows a decline in the institutional population during that same period of time.

I think, also, with the community-based waiver program that is now coming into effect, and with some modifications on that, you are going to accelerate that process.

Senator **Chafee**. That is all medicaid, though; there are no capital funds involved.

Mr. **Decker**. That is true, sir. But I think there are some ways of utilizing the medicaid waiver program in order to further accelerate the process.

I have been a superintendent of a large State institution in Idaho, and we own and operate group homes, independent living situations, apartment living situations, as well as ICF/MR facilities at the current time, so I have seen this whole spectrum. I honestly believe that there has been significant progress. I think every State in the United States has seen a decrease in the population of their institutions; I don't think that there are any that haven't I am not sure about that, but I know that the people who have testified here today have all indicated that there has been a tremendous decrease in their population I think you are going to see that with the community-based waiver program in effect.

Senator CHAFEE. Well, I think that the hierarchy is clearly tilted toward the institution. Nearly every institution has a large, strong union. The unions are frightened of moving toward the community-based care systems.

In our State, and Dr. Carl and the others could testify to this, the unions have cooperated and they haven't lost. But that's the unknown; other unions don't know that.

I suspect most parents groups are opposed to this, because they don't know what is going to happen, they are worried, and I can understand those concerns.

So, the thrust is for the continuance of what exists now—namely, the large institution. And while the population has gone down, which is splendid, it hasn't gone down dramatically in most States. So the money is being poured into upgrading these institutions instead of going out to the kind of programs and care that Sister Barbara is talking about and that others have mentioned. That is why we are seeking this thrust from the Federal Government.

Thank you all for coming. I appreciate it.

Senator CHAFEE. Yes, Sister Barbara.

Sister BARBARA EIRICH. Senator, I would like to thank you very, very much for having the opportunity to be here today. It could only happen in America. Thank you.

Senator DURENBERGER. All right. Thank you all very much. I appreciate that. [Applause.]

Our next panel consists of John Clarke of Denver, Colo., father of a retarded son; my good friend Mel Heckt from Minneapolis, father of a retarded daughter; Christine Craddy, Cranston, R.I., former resident of an institution; Peter Kinzler, on behalf of the Parents' Network and Parents Associates of the Northern Virginia Training Center, Alexandria, Va.; and Eileen LeVasseur, Barrington, R.I., mother of a retarded child.

All right. Let's start with John Clarke.

Dr. Clarke, welcome.

I guess you have all been here long enough, you know what the rules are. Your statements are all made part of the record, and you may summarize them in 2 minutes.

Dr. CLARKE. Yes, sir.

STATEMENT OF JOHN CLARKE, PH.D., FATHER OF RETARDED SON, DENVER, COLO.

Dr. CLARKE. My name is John Clarke. I am a clinical psychologist by training, and I am the parent of a young man who has been in a State institution in Colorado for about the last 10 years.

Roger has been diagnosed as "profoundly mentally retarded, of unknown ideology."

Several years ago, I was strongly opposed to the movement from institutions toward the community. In Colorado we had no choice in that matter. We were told that they were going to reduce the institution population by about 30 percent in a couple or 3 years.

My association, which is the Ridge Association for Retarded Citizens at that point opposed such a move. That was probably the beginning of a change in sentiment for me and for many other of the parents in the Ridge Association. Among other things, we found out that that move to the community actually worked, even though my son was not one of the fortunate persons to benefit from it.

Well, along about the same time I also had the opportunity to visit a number of model programs around the country, including some in the Philadelphia area, Macomb-Oakland in Michigan, and in Nebraska.

The point that I gathered from that was that these kinds of programs work, and they work extremely well. In fact, I came away convinced that they work better than do the programs in the institutions. Partly, this is a matter of attitude as much as anything else, and a lot of other intangibles, but nevertheless it left me impressed.

By the time that I had finished these experiences, both locally and nationally, I was convinced that the community alternative is the better alternative.

I would like for my son to be able to increase his responsibilities. He has not, in general, been ill-treated in the institution. There are good staff there. There are kind staff there. In fact, sometimes they are too kind; they do too much for him. And this can happen elsewhere, as well. But I think it is more likely to happen in an institutional setting, particularly where there are wards of several individuals, 20 or more. And I realize that that's not necessarily the only way it has to be.

Obviously, I could talk at great length. I would simply like to say that when I and my wife made the decision to place Roger in an institution, we didn't have the choice of a good community program; in fact, we didn't have the choice of any community program. Had we had that choice, we would not have opted for an institutional placement. So I see no reason to change my mind about that now.

Thank you.

Senator **Durenberger**. Thank you very much.

Mel Heckt.

[Dr. Clarke's prepared statement follows:]

TESTIMONY OF

JOHN R. CLARKE, PH.D.
6338 E. MISSISSIPPI ST.
DENVER, COLORADO 80204

TO THE

UNITED STATES SENATE
FINANCE COMMITTEE
SUBCOMMITTEE ON HEALTH

RE: S.2053
THE COMMUNITY AND FAMILY LIVING
AMENDMENTS OF 1983

February 27, 1983

Senate Dirksen Building
Room 215
Washington, D.C.

My name is John Clarke. I reside at 6338 East Mississippi Street in Denver, Colorado. I am a licensed Ph.D. Clinical Psychologist and practice in my firm, Colorado Rehabilitation and Clinical Consultants. I am also the parent of a son, Roger, age 20 who resides in a Colorado state institution certified as an ICF-MR for the purpose of receiving federal medicaid funds at a current rate exceeding $100/day plus funds for his education.

During the past several years I have had a number of opportunities which most parents have not. I have traveled outside of Colorado to visit community services which have been recognized for being exemplary; in particular, a number of the programs outside of Philadelphia for persons who have left Pennhurst under court order, the Macomb-Oakland Regional Center in Michigan which has returned 1200 people from institutions to the community in 10 years and has not admitted anyone to an institution in the past 5 years, and Region V in Nebraska (Lincoln and surrounding communities). I have also been fortunate to attend a number of seminars and workshops in Colorado by "state of the art" practitioners such as the late Dr. Marc Gold, Dr. John McGee, Dr. Jerry Goff, Dr. Lou Brown and Karen Green and to visit several of the newly developed community programs in Colorado. All of these experiences have changed my views on services for persons with developmental disabilities. They have clearly demonstrated to me that anyone can have his/her needs appropriately met in the community. It is being done, it can be done and it must be done.

My observations are also consistent with the very compelling data seen in the longitudinal research over four years on the Pennhurst populations reported by Jim Conroy at Temple University and Valerie Bradley at HSRI, Boston. Their research, the most rigorous scientific design using matched samples or functional twins, clearly presents data that cannot be argued away by personal opinions and emotions. The results indicate that all individuals, regardless of severity of disability, continue to make significant developmental gains leading toward reduced dependency by living in home-like community settings. Unfortunately, their counterparts who have been left behind in the institution, at a reported cost of $165/day, are making no developmental gains; indeed, a painful indictment of Pennhurst, and perhaps large congregate care residences in general. Institutional environments are not conducive to individualized programming, growth and development.

The technological revolution of the past decade has been invigorating, yet I believe that it is but a glimpse of what the future holds in special education, vocational training, non-aversive behavioral psychology, physical/occupational therapy, adaptive equipment and bioengineering. What we know today - let alone what is yet to come - can make the future brighter for all persons with developmental disabilities and their families; however, incentives for states to continue funding institutions with medicaid funds could maintain the status quo and prevent this bright future and emancipation.

At this point I would like to share my personal perspective as it relates to my own son. Roger is now 20 years of age and has resided at the Wheatridge Regional Center for about 10 years. The decision to place him was extremely difficult for his mother and me. We did not select institutional placement as our first choice nor did any of the other parents I know who placed their children in Wheatridge. When my wife and I realized that we could not give our son the care and attention he needed, we could find no family support services nor program in the community that was right for him. Had community programs been available we would have placed him in a community program.

There have been substantial changes and new developments in recent years as I mentioned previously. If I could put myself in the shoes of younger parents with younger children I would clearly and unequivocally strive to keep my child at home with family support services or if necessary, place my child in a community living arrangment. There is no question in my mind that such alternatives are superior to institutional placement. I have never seen a program that is provided in the institution that cannot be provided in the community and which is usually done better. I am aware that good programs don't always exist in some communities and that the "state of the art" technology has not been replicated in all communities. It seems clear to me that Senate Bill 2053 provides the impetus to create such programs throughout the land and give them financial incentives and stability.

I am not advocating that institutions simply be closed. I do not want my son dumped into just any kind of program but I do want him to have the opportunity to benefit from the best technological developments, to live in a homelike setting and to participate in community life just like you and me - to experience success and failure, happiness and sadness and the dignity of personal identity. It is the job of parents such as myself to work with the agencies which have the responsibility for developing programs for persons with developmental disabilities to assure that a full array of quality services are developed in the community.

As a final comment I would like to note that my impressions of Roger's experiences at Wheatridge have been mixed. In general, he has been kindly treated and there are many good and dedicated staff members. On the other hand, his programming has been sporadic at best, particularly in the early years. There were long periods of time when he received very little, if any, meaningful programming. Only in the past two years has the situation changed and even then, the impetus came from outside the institution because of the passage of federal legislation (P.L. 94-142) and a Right to Education Lawsuit for Colorado children residing in institutions.

Roger is presently in an institution based school program and this experience has been generally positive; however, he has not had the kind of daily opportunities for social interaction and age appropriate peer modeling, which would be most desirable. He never sees anyone in a better state than he is. He has no opportunity to learn from role models who are not handicapped. Unfortunately, when he reaches age 21 it is quite uncertain whether he will be able to continue to receive adequate proramming. In other words, the programs developed at the institution came about as a result of outside pressures and may not continue when Roger "graduates" from school. Most of the adults residing at Ridge today get almost no developmental programming!

Right now we are at a critical stage of development for Roger and many other young adults. It is extremely timely and essential that the federal government shift its financial bias from institutions and congregate care to community program development so that these young people will have a chance to develop. You have heard and will continue to hear outcries from both parents who are losing the perceived security of the institution and the representatives of the industries we have created over the past thirteen years through the ICF-MR medicaid program. Listen to their concerns and provide the necessary safeguards to insure continuity of funds and services during the transition. However, I urge you to rise above the emotionalism and vested interests and provide the statesmanship and leadership for public policy which has been entrusted to you for the good of all of society. Ensuing generations should not have institutions forced upon them as it was upon us! We must provide the next generation with a better legacy. The future for children and adults with developmental disabilities is in your hands. I urge you to support S.2053.

STATEMENT OF MELVIN D. HECKT, FATHER OF RETARDED DAUGHTER, MINNEAPOLIS, MINN.

Mr. HECKT. Thank you, Senator Durenberger.

I am a Minneapolis lawyer and father of a young lady, Janice, age 32, who is severely mentally retarded. Her home is the Faribault State Hospital in Minnesota.

I would like to speak on behalf of Janice and on behalf of many parents who have profoundly and severely retarded sons and daughters who live in our Minnesota State institutions and in our 41 Minnesota community institutions.

First I would like to express to Congress, however, our deep appreciation to each Member of Congress for the medicaid law and appropriations, which have enabled my State to make substantial improvement in the quality of care for the 2,211 residents in our State institutions, of which we have 7. Also, we have increased the quality of care for over 5,000 residents of our 311 community residential facilities, all of which are funded by ICF/MR medicaid funding. They are not nursing homes, however. And we have 2,300 of those 5,000 who live in 41 community institutions.

Our success today, and I think we have made tremendous success in improving the quality of care in both the State institutions and in the community residential development, has been attributable in large part to the Federal-State medicaid match.

I would like to suggest, however, that we are definitely opposed to this Senate bill, because we feel that almost all institutions would close, or they would return to the warehousing of the past. We are opposed to that. We think there are good and bad, and we don't believe that we should close down all of our State institutions and community institutions any more than we should all nursing homes because there are some bad ones in the country there.

We also think that parents and retarded people would lose the freedom to chose what is most appropriate, the institution or the small community home, among all of the options. We think it is very important that parents have this right to play a very important role in the determination of what is best.

Sometimes the government people come and go, but the parents are still there, and sometimes the monitors don't always have all the facts and the information on a specific child as to knowing what is best or isn't best.

In conclusion, we are also concerned about the fact that there will be many, many thousands of people dumped into inappropriate community residential facilities if this bill were passed. Such has happened in Illinois, Chicago, where my daughter was a social worker, and some of them being dumped into downtown Chicago hotels. We feel this is a very, very severe problem in this area. And I think moving almost 2,000 people who live in places over 15 beds in our Nation would be a mind-boggling task. Many of them have satisfactory placements, and some don't.

There ought to be a right for those people who want to move into the community to go into the community; but there should also be a right for those who believe that the best treatment program is the institution. They should have that right, too. We don't see how that can operate under S. 2053.

We would recommend that the bill be withdrawn and the Federal Government not force or plan closure of all or almost all institutions now; the state of knowledge is too soft. We think States must decide or have a major role in any such closure decision, and we think that we do need more experience with the waiver law, the community care waiver law, to remove some of the bugs out of that.

We do also, however, fully support you, Senator Chafee, as far as your ideas of extending medicaid funding to more and additional community services. We think that can make a lot of sense for many, but not for all. We think increased appropriations in those areas would save tax dollars in the long run, by the delay or diversion from the more expensive community and State institutions.

Thank you very much.

[Mr. Heckt's prepared statement follows:]

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Testimony

of

MELVIN D. HECKT
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before the

SUBCOMMITTEE ON HEALTH

of the

UNITED STATES SENATE
COMMITTEE ON FINANCE

on

Community and Family Living Amendment of 1983
S.2053

February 27, 1984

WASHINGTON, D.C.

Summary of Points

I Federal Medicaid should not be withdrawn from all state and community institutions.

- a. Almost all would close or return to the warehousing of the past.
- b. Parents and/or retarded people would lose the freedom to choose--the institution or the small community home as the most appropriate and least restrictive.
- c. If would dump many out of institutions against their wills, and their parents wills, and into inappropriate community residences and services.
- d. It would deny residential and other services to those who have no alternative.
- e. It would damage the already low self-esteem of those who are admitted and then demitted from the small homes.
- f. The mass transfer of all is draconian and mindboggling - the human suffering of residents, parents and employees - the economic loss and waste.

II. S-2053's arbitrary small limitations for all future residences should be rejected.

III. Federal Medicaid should be extended to community services in S-2053.

- a. It is good for many, but not for all.
- b. Increased appropriations now should save tax dollars in the future by prevention or delay and diversion from the more expensive community and state institutions.

IV. **Recommendations**

- a. S.2053 should be withdrawn or killed NOW.
- b. The Federal Government should not force or plan closure of all or most institutions now. The state of knowledge is too soft.
- c. States must decide, or play a major role in, any such closure decision.
- d. More experience with and study of the federal "Community Care Waiver" law is necessary.

I am Melvin D. Heckt, a Minneapolis lawyer, and father of Janice, age 32, a severely mentally retarded young lady whose home is the Faribault State Hospital.

I speak on behalf of my daughter, and for many parents, relatives and guardians of citizens who are mentally retarded and who live in state or community institutions.

May I express our deepest appreciation to you, Senator Durenberger, and to each member of this subcommittee, and to Congress for the Medicaid law and appropriations which have enabled my state to make substantial improvement in the quality of care for the 2,211 residents in our eight (8) state institutions, and for the 5,000 residents of our 300+ community ICFMR facilities, of which 2,300 residents live in 41 community institutions. Our success today would not have been possible without federal and state Medicaid funding.

For 30 years, I have joined with other members of the Association for Retarded Citizens in fighting the long battle for the development, expansion and improvement of community and institutional services for all citizens who are mentally retarded. As a consequence of that involvement, study and experience, I strongly support extending federal Medicaid funding to those additional community services provided in S.2053, and just as resolutely oppose both the withdrawal of substantially all of that Medicaid funding from all state and community institutions, and the arbitrary size limitations for new community residential facilities contained in the bill.

S.2053 represents the worst of all worlds for many mentally retarded citizens who reside appropriately in state and community institutions if Medicaid funding is withdrawn, and the best of all worlds for many infants, children and adults who appropriately could continue to live with their parents, or in foster homes, group homes or semi-independent living facilities only if Medicaid funding is provided.

S.2053 THE WORST OF ALL WORLDS

However well-intended, S.2053, the "Community and Family Living Amendments of 1983", requires of its supporters an irresponsible leap into dangerously uncertain waters. The architects of this questionably designed and imprudently proposed legislation have advanced a blueprint which creates many more problems than it seeks to correct.

Based on my independent examination of widely dispersed research studies, conversations with hundreds of parents and numerous experts, and my own personal experience, I am convinced that if S.2053 is adopted, most, if not all, of the following results would develop from the incautious leap previously mentioned:

1. All state institutions would be closed in 10 years or less, or, if some states decided to fund the entire cost of those institutions, the quality of service would return dangerously close to the warehousing and substandard care which prevailed in them so disgracefully 15 years ago or such states might maintain existing standards, pay the entire cost of said institutions, and reduce the funding of existing necessary community services by the amount of the loss of the federal Medicaid funds.

2. Almost all community institutions (defined as those having more than 15 beds) would be forced to close their doors to mentally retarded citizens in 10 or 15 years because those community institutions in many states derive 45 to 80 per centum of their operating costs from federal Medicaid funding.

3. S.2053 would deny to mentally retarded persons, and to their parents, relatives and/or guardians, the right to choose the state or community institution as the most appropriate and least restrictive among the current options.

4. S.2053, in a baronial disregard of parental wishes or opinion concerning the best interest of their retarded sons and daughters, would force many mentally retarded people - against their wills, and against the wills of their parents, relatives and/or guardians - to leave appropriate community and state institutions, and would dump them, almost indifferently, into inappropriate community residential facilities. Ironically, that ill-chosen curtailment of residential and programatic options would, at the same time, deny appropriate small group home community services for those who now live in community or institution settings, but who want and are able to live in smaller community facilities, yet could not secure admission to them because beds and programming would be taken by those from the institutions who would be transferred to them inappropriately and unwillingly.

5. The bill's untested and excessively risky "solution" would force the removal nation-wide of almost 180,000 retarded persons from existing state and community facilities which have more than 15 beds. The turnover problem inherent in such a mass transfer of mentally retarded persons is as mindboggling as its ramifications are endless. It is draconian. It is difficult to predict the economic cost and human suffering of such a move.

6. This proposed legislation would deny residential and programatic services to those who have no alternative but a state or community institution. This is true especially for those profoundly and severely and multiply handicapped retarded who live in sparsely populated areas of America, and who require 24-hour nursing, and other professional care. It also eliminates a vital resource for those who have been demitted from the foster or small group home, or whose foster or group homes have gone out of business, or lost their licenses, or who have tried the small foster or group homes and found living in them unbearable. It is safe to say that sometimes 6 normal adults or 6 retarded adults cannot live under the same roof. Parenthetically, it is important to note that in the past several years, most admissions to Minnesota's state institutions have been those discharged from group homes or other community facilities.

7. The closure of all state and community institutions will result (notwithstanding the best intentions of the bureaucracy) in many residents now therein being unloaded, nil admirari, into inappropriate community residences and ineffective programs. What is even more horrifying to consider is the possibility that those unloaded will be provided with no program or residential service whatsoever.

In the past, the efforts of some states to reduce institution populations have resulted in horrible dumping. Indiana dumped 4,000 institutionalized residents into nursing homes without adequate programs. Illinois unloaded thousands into huge, rundown, downtown Chicago hotels located in high crime areas. Missouri's plan was nearly a shambles, and even in Minnesota, which to date has an excellent record of reducing its mentally retarded state institutionalized population, there has been some dumping of young adults into nursing homes for the elderly, and others into larger, more restrictive community environments than existed in their former state institution home. Others have been injured by medically prescribed drug overdoses in the community, and have had to return to the institution.

I am not convinced that the monitoring, licensing and individual program plans will eliminate dumping if the federal and state dollars stop flowing.

8. However unintentional, and perhaps totally overlooked, consider the psychological damage facing those residents who, for the sake of expediency, are transferred to group homes, and then are kicked out. If they know their self esteem is low, what explanation can be given to those so afflicted that will abrogate the further decline of self worth brought on by

another, and then another, and then another dismissal? Not all of the elderly retarded residents in institutions are Bill Sackters; nor will all have the good fortune to find such good and supportive friends as Bill. Some have lived in the institution for 50 or more years, and do not wish to leave. How can we totally disregard their feelings, and their rights? Some retarded people of all ages exhibit great difficulty adjusting to change. Others can adjust. But still others cannot make changes without disastrous results.

9. S.2053 leaps recklessly to a number of incorrect conclusions and unsupportable assumptions. Among these is the notion that adequate monitoring of small group homes will be guaranteed. Under other less crucial circumstances, if that idea were not so pretentious, it might be described as quaint. For example, if Minnesota were to require 6-to-a-household limitations for those currently residing in our state's ICFMRs, and in our state institutions, it would need 1,182 community residential facilities as opposed to the present 300+ ICFMRs and eight (8) state institutions now in service. The cost of monitoring those additional facilities necessitated by S.2053 would be gigantic; the dumping and demissions would be catastrophic; and, administratively, an ongoing nightmare would be created. Quis custodiet ipsos custodes?

10. Among other less less-than-infallible conclusions drawn by the promoters of S.2053 is the claim that costs are less expensive and living conditions are better for all mentally retarded citizens if they reside in small foster or group homes in the community rather than in state or community institutions. Nothing resembling acceptable evidence is offered in support of that claim. Conversely, from across the nation, and within many disciplines, respected voices are heard cautioning against premature acceptance of the studies projecting large cost-savings or superior living conditions for all mentally retarded people if only they move lock-step into the small foster or group homes in the community. The more realistic expectation is that the proponents claim is correct for some and incorrect for others. Exaggerated projections of cost-savings can only come back to haunt many retarded citizens in time.

11. The same thesis further declares that if all state and community institutions were to be closed within 10 to 15 years, automatically small foster or group homes would be located, developed, funded and staffed with experienced and caring employees for those mentally retarded persons who have been discharged from them, and also for those living at home but in desperate need of such community services. Again, that helter

skelter plunge into unchartered waters. One almost would conclude that the proponents have overlooked a number of salient problems. For example, high interest rates, high building costs, housing shortages, low per diem rates for profit and non-profit providers, unwillingness of some states to appropriate more tax dollars, the logistical problems of closure and locating new facilities; all have a significant bearing upon achieving the proponent's objective.

Likewise, how can state or community institutions continue to reduce their populations, and revenues, and still meet the high standards established by S.2053 and not be sued under Sec. 5 (a)(i) et seq? Does anyone actually believe that such a massive nationwide shift of people can be well-coordinated among all of the cooperating county, state and federal agencies?

Now, for the purpose of clarity and openness, and wishing to state my unease with S.2053 as specifically as possible, may I ask the subcommittee to consider the following questions and criticisms:

1. Page 2 - Lines 21-31 (b) (2) (3).

   Unless changed, this section would deny medical assistance to persons who have resided in an institution for a period of two years, and who have no other alternative for residential placement. Likewise, I think it is both ridiculous and cruel to designate such a short time duration for care, treatment, and habilitation of some persons who are mentally retarded.

2. Page 3 - (c) (1) (D) Specialized Vocational Services

   Is it not conceivable that the inclusion of vocational and employment services in medical assistance funding might drain off dollars for existing services to such an extent that now in-place community services will receive less funding than at present?

   If that be the case, then I believe that some of these services should be excluded from medical assistance funding.

3. Page 6 - Lines 7-18 (2) (B) (i) and (ii).

   Exceptions and alternatives must be provided to any bed size limitation for a facility. This does not distinguish between the need for providing residential services for children apart from those established for adults and severely retarded, and it fails to consider the special needs of the profoundly multiply handicapped, high intensive medial and 24-hour nursing care person as contrasted with the mildly or moderately retarded person without such handicaps.

   (C) Line 25 (iii)

   The suggestion that in order to receive medical assistance, all profoundly retarded, multiply handicapped people shall be located in residential neighborhoods, wherein they would be encouraged and enabled to participate in the prevailing living, working and service patterns of such neighborhoods, either amounts to a classic case of sheer folly or represents another definition of the word PROFOUNDLY.

4. Pages 6 and 7 - (h) (2) (D) (i)

In the section defining the inter-disciplinary team, S.2053 states that professionals and retarded people shall be part of the team, and "when appropriate, the parents, guardians, next of kin, or next friend of such individual" may be involved.

Does it not seem more-than-somewhat illogical to insist that a profoundly retarded person who can't understand or communicate or make certain decisions be given a place on the inter-disciplinary team while, at the same time, denying membership to a parent because someone, presumably a professional, has determined that the participation of a parent, relative or guardian is irrelevant "to the habilitation or rehabilitation of such individual."

Parents of profoundly and severely retarded sons and daughters have been making many decisions for the lifetimes of those persons who do not have the ability to do so. How can anyone summarily pre-empt from them that natural right? Or deny to them that loving involvement? Before a parent is precluded from inter-disciplinary team participation, should not the Court so order that exclusion?

5. Page 8 - Line 2 (B)

Though the plan calls for continuity of medical assistance for severely disabled individuals who reside in a facility or institution that ceases to function, it provides no assurance whatever for the continuation of residential services.

(F) Refers to a periodic independent monitoring or review of the quality of medical assistance provided, but fails to specify the time intervals involved. Could they be ten years apart?

6. Page 9 - Line 6 (H)

Deals with maximum efforts made to provide employment of former institution employees affected by the transfer of severely disabled individuals to community facilities, but nowhere in S.2053 appears anything resembling assurance or guarantee that those efforts will produce positive results. Other questions regarding employee loss are ignored or overlooked. Herewith, a sampling:

(a) If S.2053 passes, will not the best professionals, and lay staff, depart the facility as quickly as possible? Who would remain facing sure dismissal in 10-years, or less? May that not have an adverse affect upon many residents?

(b) What of the former mentally retarded residents who are now gainfully employed at institutions? About 50 such workers are presently employed in Minnesota? Is it reasonable to think that they will be able to find employment elsewhere?

(c) Many institutions have excellent ongoing in-service training programs for those who work with the mentally retarded and other handicapped persons. How can we retain the experience, know-how and priceless empathy and enthusiasm of those employees if we threaten their jobs?

7. Page 11

Temporary Increase in Federal Payment - Section 3 (7)

The 5 per centum incentive to place severely disabled persons in the community promises dumping just as surely as the counties' financial incentive to place them in institutions guaranteed it. Both were/are wrong. Appropriate placement must be the prevailing criteria. Incentives of a fiscal nature can only insure dumping.

Forced to confront the possibility that S.2053 might be enacted, I find myself caught in a crossfire of frustration, astonishment, uncertainty and parental concern - a combination of eviscerating emotions not unlike the helplessness felt by a black person who was denied the right to vote, forced to sit in the rear of a bus and refused the freedom to eat in a public restaurant.

My daughter, and thousands of mentally retarded persons like her, by this legislation will be told that they have been denied the right, and the choice, to live either in a state institution or a community-based facility if any of these abodes exceed the new, mandatory resident limits established by S.2053. Instead, imperiously, they will be forced to live in a house sheltering from 1 to 15 residents, in a community not of their choosing, a facility chosen for them by some professional or governmental expert(s) who may or may not be governed by what is most appropriate, but rather by how little it costs.

Senator Durenberger, members of the subcommittee, at this point I should like to share with you some of the feelings, opinions, and sentiments contained in letters I have received from other parents and guardians concerning the enactment of S.2053.

"...As with all human beings, there is no 'Oneness' to the retarded population, but a complicated array malfunction within an already complicated structure of human existence. What must be established is a system of care that is capable of matching the myriad of needs present in the regarded population."

DEAN F. THOMAS,
Minneapolis, Minnesota

"...Unless all the resources available at an institution are made available in the community, this proposed legislation is not feasible. Even today, in small outstate communities many of these resources are not available for those already released from State Hospitals. I strongly oppose S.2053 and implore that you and your committee consider this piece of legislation for what it is, a totally inappropriate bill that does NOT protect the best interest of any retarded person."

BERNICE UPIN,
Faribault, Minnesota

"...To rule, as in S.2053, that all mentally retarded Americans must exist in small groups of fifteen beds or less is cruel, thoughtless, and brutal. We need community and state institutions for that portion of the mentally retarded population who need significant, supportive services that a group home could not provide."

FLORENCE M. FISKUM,
Minneapolis, Minnesota

"...The 'retarded' are not ONE group with one problem and therefore one solution. Like all the rest of society, each retarded person is an individual, and what is a good living situation for one may or may not work for another. Please consider all of the possible implications of this amendment. Do not be unduly influenced by its introduction by the Governmental Affairs Committee of ARC-US. So called 'experts' have been wrong many times in the past."

MARIAN D. HELLING
Richfield, Minnesota

"...Horrified at our first encounter with a state institution some eighteen (18) years ago and watching the slow but progressive movement to the present makes us want to sing praises to all the people involved in the program. They have done a tremendous job. Please do not allow it to slide backward. In our opinion there is no best way for all. Some people fit well in residential facilities. Our profoundly retarded son would not fit this mold. He needs close supervsion and he needs training. He is receiving that now and we think he is deserving of it. Our feelings are strong that it would be near impossible for him to receive the same in a small unit somewhere else with small staffing, different caring and attitudes."

MR. & MRS. RICHARD SCHULTZ
Bloomington, Minnesota

"...The end result would be to force large numbers of retarded citizens from their present satisfactory placement in community and state institutions and dump them into inappropriate residential facilities that might or might not be available; all this without the retarded citizens, their parents' relatives' or guardians' input on planning or decision making."

GORDON S. LUNDBERG
Richfield, Minnesota

"...Not to mention the exodus that would occur, from them being transferred from home to home, until one at the bottom of the scale would accept them; to a place, no doubt, where their only interest is making a buck, and the care is non-existent. As an example, I have a twin brother that is retarded who has happily spent most of his 62 years of life in the campus like surroundings of the Faribault State Hospital, where he has always had good care by the staff, who genuinely care about him; who is also wheelchair ridden, and needs a big facility like Faribault with its spacious grounds to roam around in."

LESTER D. LEONARDSON
St. Paul, Minnesota

> "...At some point in our lives we are all affected by a mentally retarded person, whether it be our child, a brother or sister, a niece or nephew, or relative of one whom we are associated with. It is a sad commentary that still we are fighting for the rights of the mentally retarded. I urge you to oppose S.2053. I have seen both sides of the coin, having a mentally retarded brother and being a teacher of the mentally retarded.
> I would like to request...that you "unofficially" spend a day with profoundly and severely retarded persons, and justify the passage of S.2053..."

BETSY PRATT LONG
Tulsa, Oklahoma

> "...One of the premises behind S.2053 is that mentally retarded citizens can and should enjoy the right to move in larger society at will. Many are capable of this, they can go to a job or a movie alone, and there are currently homes (maybe more are needed) that can meet their needs. However, there are many retarded citizens who are not capable of these kinds of activities, who cannot care for themselves or venture into larger society, and to whom living with a large group of peers is of greater concern. To force these individuals to live in a small home with only a few others with whom they can interact is inhumane...."

DANIEL M. FISKUM
St. Paul, Minnesota

BEST OF ALL WORLDS

S.2053 does have some very outstanding provisions which should be approved by Congress. Medicaid should be extended to cover some of these costs:

1. Parents, who otherwise would have to institutionalize their infant or child, should be given medical assistance to enable them to choose to keep their child at home whenever possible. This option may be best for the child and the

parent. In most cases, the cost would be much less than that of the state or community institution or the ICMFR group home. In some instances, the cost may exceed that of the institution, but the child's interest should prevail over the cost argument. Likewise, cost considerations should not force parents to keep the child at home if it is not feasible to do so. Some families can cope while others might be destroyed by having such a child in the home.

2. Foster parents should be an option for children who can't live at home. However, mass usage of foster parents is also fraught with potential for abuse and difficulty in monitoring. For those profoundly and severely retarded who have need of 24-hour nursing care, or who have severe behavioral problems, it may be much more difficult to find such foster parents than some experts admit, and also such foster parents may suffer from the same burn-out as the natural parents. Stability and continuity of care is very important! The use of foster parents for normal children has frequently resulted in some of those children being shunted from foster home to foster home with dire consequences for the child.

3. Small foster homes which need not meet ICFMR standards and regulations are another viable option for some, but certainly not all, mentally retarded citizens.

4. Semi-independent living is another viable option for some mildly and moderately retarded adult citizens. Again, each

individual must be carefully evaluated or disastrous results can and do occur from improper placement. This would not be proper for profoundly retarded adults or for most severely retarded adults.

5. Also, the small ICFMR group home should be a viable option for some of the retarded now living in our state and community institutions. They, and their parents, should have the right to choose and secure admission to such facilities. However, the small group home is not the answer for all children or adults.

In other words, creating more options by extending Medicaid funding gives parents and their sons and daughters a much better opportunity to find the proper residence and program. The prevention, delay or diversion from placement in a more expensive institution or ICFMR facility will save costs for our taxpayers and be better for those who can benefit therefrom. However, too much precaution cannot be taken to prevent cost from being the sole or most compelling criteria in determining what is or is not proper care for the individual person. In Minnesota, I understand that some counties are inappropriately pushing foster home placements for cost reasons only.

Such an extension of Medicaid to those community and family services mentioned above will not eliminate the need for community and state institutions or for ICFMR group homes, but it will hopefully reduce the demand for more of such services and in this way reduce this cost pressure.

There is one other danger I believe should be addressed. Unless Congress and the states increase appropriations in the short run for such family and community services, there is a real danger and probability that present services funded by Medicaid will suffer cut-backs in funding which may substantially curtail the quality of services presently being provided. In the long run, however, such an extension of Medicaid should reduce the amount of or need for increased funding.

THE PROPONENTS POSITION

The proponents of S.2053 obviously believe that all state and community institutions are bad and that all existing community facilities having 15 beds or less are passable, but in the future nothing should be funded by Medicaid if larger than 3 times the average family household size which in my state would be 8.

In trying to convince you that all institutions are bad, they show you publicity of Pennhurst and Willowbrook and I understand Senator Weicker's committee is investigating the 10 worst institutions in the nation, as opposed to any investigation of the best.

They and the media only point out the bad and not the good in our institutions. They should realize that all state and community services, including all residential facilities, vary from quite poor to quite good. Because some are quite poor does this mean we should destroy all? In our nation there are some bad and excellent nursing homes. Should Congress withdraw all Medicaid funding from all nursing homes because some are bad? Of course not! There are recent developments enabling some who want to live in their homes or in smaller less expensive facilities to receive Medicaid assistance. This makes sense!

The proponents also overlook the vast improvements in physical plants and staffing and individualized programming which have occurred recently in our state and community institutions since the advent of the 1977 ICFMR Law. Many of these improvements have taken place in the past 3 years.

The proponents arrogantly persist in trying to place all mentally retarded people and their parents in the same lock-step, iron pants mold. The proponents know best and the thousands and thousands of parents who have sons and daughters residing in state and community institutions are all wrong. The proponents fail to realize that many of our retarded sons and daughters have much more freedom, much less restriction, much safer surroundings and a more professionally supportive, more loving and happy environment in the larger facility than they would receive in the small group home for 6 or less.

Some of the proponents advance cost saving as the rationale for institution closure, but many now are backing away from that position. In 1963, Minnesota had 6,100 residents in state institutions. This was reduced to 2,300 plus at the end of

1982. To compare the cost of care of the mildly and moderately and even severely retarded who live in community homes with the cost of caring for those profoundly and severely retarded who now remain in the institutions is comparing apples with oranges.

Recommendations

a. S.2053 should be withdrawn or killed now.

b. The Federal Government should not force or plan closure of all or most institutions now. The state of knowledge is too soft.

c. States must decide, or play a major role in, any such closure decision.

d. More experience with and study of the federal "Community Care Waiver" law is necessary. Why? To insure that placement decisions are in fact being made based upon what is most appropriate for each individual and not made upon what is the least costly. Otherwise there will surely be massive dumping or forcing of mentally retarded people out of the State and Community institutions and ICFMR Group Homes into inappropriate small community residences. This would be true whether closure or forced reduction of population were involved.

CONCLUSION

No person who is mentally retarded should be denied the right to live in either a community or in a State or Community institution. Nor should such person be obligated to live in either because there are no other viable options.

The proponants of S-2053 are willing to upset or destroy the entire cart in order to find a few bad apples. The bad apples may be found by this method but the good ones have then already been dumped out.

I appreciate the opportunity to appear before you and to submit this written statement. I am confident this Subcommittee will do what is just and right.

Melvin D. Heckt

Senator **Durenberger**. Thank you very much.

Senator Chafee.

Senator **Chafee**. The next witness will be Christine Craddy, from Cranston, who was formerly in one of our institutions in Rhode Island.

All right, Christine, go to it.

STATEMENT OF CHRISTINE CRADDY, CRANSTON, R.I., FORMER RESIDENT OF AN INSTITUTION

Ms. **Craddy**. Mr. Chairman, I have something very important to tell you. I used to live at Ladd School, since I was 5 years old. Now I am out in the community living in a group home with eight other people—banking, shopping, doing my own haircuts.

The food was very terrible. We used to be the last building to eat. It was very cold. I didn't have very much * * *. The clothes didn't fit. My relatives used to buy me new clothes—they used to lose them. And I don't think anybody else should live in an institution. If you are going to put them anywhere, put them in a group home.

Thank you.

Senator **Durenberger**. Thank you, Christine. [Applause.]

[Ms. Craddy's prepared statement follows:]

TESTIMONY

provided to the
Senate Sub-Committee on Health
on
S.2053

by Christine Craddy
635 Dyer Avenue
Cranston, RI 02920

S.2053

My name is Christine Craddy and I am a resident of a group home in Cranston, Rhode Island.

I lived in an institution, called Ladd School, from the time I was five (5) years old until I was nineteen (19).

When I was at Ladd, I was scared most of the time and I was very lonely. Sometimes I would go home on weekends and when I was taken back to Ladd I would cry for a long time.

Most of the time at Ladd we would watch television all day. Lots of times I wore clothes that didn't fit. I think that we were the last building to get fed because the food was always cold and it wasn't very good.

At Ladd I spent all of my time in a wheelchair. Now I use a walker and I even go to the dance on Friday night. When I dance I don't need the walker.

I have lived in the group home for eight (8) years now, and I am very happy.

I have come a long way -- from braces to special shoes and from a wheelchair to a walker.

S.2053
Christine Craddy
Page 2

In the group home I help make supper, do my own laundry, go shopping and pay for the hairdresser myself.

At Ladd I used to stay in the ward all day and go to the dining hall to eat and that's about all.

Since I've been living on Dyer Avenue, I have taken trips to Virginia, Florida, New Hampshire and Canada. I saved my own money for these vacations from working at the center.

I work every day at the center. All of us are glad to be out of Ladd.

I think everybody would like to be out of Ladd. Somebody should just ask them what they would like.

Recorded by:

James V. Healey

Submitted by:

Christine Craddy

Christine Craddy

Senator **Chafee**. Thank you Christine.

Senator **Durenberger**. Our next witness will be Peter Kinzler, from Alexandria, Va.

STATEMENT OF PETER KINZLER, ON BEHALF OF THE PARENTS' NETWORK AND PARENTS AND ASSOCIATES OF THE NORTHERN VIRGINIA TRAINING CENTER, ALEXANDRIA, VA.

Mr. **Kinzler**. Thank you, Senator Durenberger.

In 1978, when I first considered putting my child in an institution, my image of an institution was probably that shared by many of the Senators and other people who have not had children there and have not had the opportunity to visit that it was a warehouse with beds lined up along a wall, people shackled in, et cetera.

Fortunately, it was not that. Quite to the contrary, the Northern Virginia Training Center is a very bright, cheery place with small units and extremely dedicated and knowledgeable staff.

When we circulated copies of Senator Chafee's bill around the country to parents' groups, we discovered that other parents were similarly satisfied. And as a result, The Parents' Network now represents 60,000 parents—people with first-hand experience—in 38 States. We suggest that institutions really deserve their new name of "training centers." It is more appropriate.

We do not object at all to community living arrangements. We think they are entirely appropriate in many situations. We think there is plenty of experience that shows they work extremely well with many mildly and moderately retarded people.

We would submit that their experience with severely and profoundly retarded is far more limited and far more questionable. There are some good experiences and there are some bad ones. For example, I have submitted for the record an experience from Florida where 16 people who were moved out of institutions into group homes died within a short period of time, largely because of lack of knowledge in the medical care.

What we need are not anecdotes, but well-analyzed data.

The cost questions are difficult ones. The studies that we have seen tend to compare apples and oranges—the mildly and moderately retarded in the community with the severely and profoundly retarded in institutions. They compare different constellations of services. Again, more serious analysis is needed.

What do we favor? What we favor, first of all, is more money. There simply is no substitute for money. Senator Chafee has referred to the fact that there may be anywhere between 750,000 and 2 million people out there who would be eligible for medicaid under his bill. How you squeeze services for all those people out of the same pot of dollars, I don't know. I don't think it is feasible.

What we think would be extremely useful would be to eliminate the existing bias in the medicaid program so that people's needs would be determinative, not the availability of funds.

Finally, if there is one thing that could be done immediately, that would be to take the mildly and moderately retarded who are in institutions who do not belong there and move those people into the communities.

Thank you, Senator.

Senator CHAFEE. Thank you, Mr. Kinzler.

The next witness is Eileen LeVasseur from Barrington, R.I.

[Mr. Kinzler's prepared statement follows:]

Principal Points of Peter Kinzler, of the Parents Network, in Opposition to S. 2053 the Community and Family Living Act Amendments of 1983

1. Parents Network represents 60,000 parents of mentally retarded children who live in institutions in 38 states.

2. We believe, on the basis of first hand experience, that most of today's institutions for the mentally retarded are well run places that provide quality care and training for our children.

3. Community living arrangements for severely and profoundly retarded persons are still in an experimental stage. To date, most community-based residences have dealt with mildly and moderately retarded people, those who can dress and feed themselves and hold jobs in the community. Community experience with severely and profoundly retarded people-- those whose trainability is very limited and who need around-the-clock care-- is very limited and has not been subjected to rigorous analysis. Many expert observers in the field suggest that other factors--such as the grouping of residents and the qualifications of staff-- are more relevant to development.

4. Existing data on the relative costs of institutions and community living arrangements are contradictory and inconclusive. Most of the studies are fatally flawed, in that they tend to compare the costs of less retarded individuals in the community with those of the more severely retarded residents of institutions, and they compare a different constellation of services. Where similar residents and services are compared, the costs appear to be about the same. There is no reliable data to support the contention that even one more person can be served for the same dollars, nevertheless that two to three times the present population could be served.

5. Parents have a number of questions about what would happen to our children in the community living arrangements envisioned in S. 2053. How would the many services now provided at institutions--from different types of therapists to medical care-- be provided ? Would bad apples among the staff be weeded out rapidly ? Could Medicaid monitor 100 times the number of living arrangements they now monitor with any reasonable assurance of maintaining quality ? What will happen to the residents who are left behind in institutions when a financial crunch occurs ?

6. Some actions can be taken now to better meet the needs of all severely and profoundly retarded people. One, the states and the federal government can provide more money. Two, the bias in Medicaid in favor of institutional funding should be eliminated, building on the present waiver program. Three, most mildly and moderately residents of institutions-- those most demonstrably capable of benefitting from living in the community-- should be moved there. Finally, we must develop a continuum of services from private homes to group homes to institutions to assure that the individual needs of the retarded-- and not the needs of those with an ideological predisposition-- are best served.

Statement of Peter Kinzler
on behalf of
the Parents' Network
and
Parents and Associates of the Northern Virginia Training Center
in opposition to
S. 2053
the Community and Family Living Act Amendments of 1983
before the Health Subcommittee
of the
Senate Finance Committee
February 27, 1984

I am testifying today as the parent of a severely to profoundly retarded son who resides in an institution, on behalf of the parents of that institution and on behalf of the Parents Network, an informal organization of more than 60,000 parents of mentally retarded children who live in institutions. The Network sprung up more or less spontaneously in the Summer of 1983 in reaction to a legislative proposal by the Association for Retarded Citizens to phase out, over a 10 to 15 year period, all Medicaid funding for institutions for the mentally retarded. This concept has been incorporated into S. 2053.

We are generally very satisfied with the care our children are receiving in today's institutions,which more accurately deserve the name "training centers." While we are well aware of the need for more community living arrangements--and fully support additional funds for their creation-- we believe they are needed to supplement, not replace, institutional care. What is needed is a continuum of care so that retarded citizens can receive the most appropriate care to fit their needs. Unfortunately, S. 2053 would fund more community living arrangements by cutting off federal Medicaid funds for institutions. This approach would surely mean the closing of most if not all institutions. Therefore, as the parents of the children who would be most directly affected by this legislation, we vehemently oppose enactment of S. 2053.

Let me state to you as clearly and succinctly as I can the basis for our opposition.

Most of Today's Institutions for the Mentally Retarded Are Well Run Places that Provide Quality Care and Training for the Residents

Thanks to years of effort by thousands of people-- including many members or former members of the Association for Retarded Citizens-- today's institutions no longer are the warehouses of the turn of the century that often come to the minds of people who do not have relatives in institutions. As parents, we could never place our children in warehouses.

Federal Medicaid funds and standards have played a major role in the dramatic improvement in the quality of institutions. My son lives on a brightly colored unit with 12 other residents and sleeps in a room with two other children. He goes out into the community for school each day and when he returns to the institution, he has training programs for eating, walking, dressing and toileting, among others. The staff is generally caring, committed and creative.

Tighter enforcement of existing Medicaid standards or adoption of even tougher standards, such as those presently being considered by the Department of Health and Human Services, could make our children's residences even better places.

To say that institutions have come a long way from the olden days is not to say that all abuses have been eliminated. There are still some instances of improper care and even violence in institutions--and every possible effort should be taken to root out these problems.

To be fair, however, one must recognize that these same problems exist in society as a whole and even in community living arrangements. For example, a series of articles in the summer of 1983, copies of which are attached for inclusion in the hearing record, recount how 16 residents of an institution who were moved into newly built group homes in Florida died soon after they were moved. The reasons for their deaths vary from improper nursing and medical care to "transfer trauma," a medical theory that some people lose the will to live after being taken from familiar surroundings. As a result of these unnecessary deaths, further transfers were halted.

I do not cite this example to suggest that these problems are rampant in community living arrangements, any more than similar anecdotal information demonstrates widespread problems in institutions. There is no comprehensive data to prove either case. The key point is that protection of the handicapped-- in and out of institutions-- is particularly crucial because most handicapped people are not capable of protecting themselves.

In short, we do not maintain that institutions are perfect residences nor that all of them are run as well as we'd like to see them run. But we do know from first hand experience that there are many well run institutions in all parts of the United States that provide significant benefits to our children. Under these circumstances, we think the advocates of legislation that would inevitably result in closing many, if not most, of our children's residences have an enormous responsibility to demonstrate that our children can be equally or better served in community-based residential facilities.

Group Homes and Related Community-based Living Facilities for Severely to Profoundly Retarded Persons Are Still in an Experimental Stage

For the most part, group homes have been used for the mildly to moderately retarded who do not have severe medical or behavorial problems. We think their track record in serving this population indicates that most such people who now live in institutions can benefit from placements in community living facilities.

However, most residents of institutions today are not mildly or moderately retarded. They cannot dress and feed themselves and hold jobs in the community. They are severely and profoundly retarded; people whose trainability is very limited and who need around-the-clock care.

The present population of institutions--where more than 76% of the residents are severely or profoundly retarded--reflects the success over the past decade of moving many mildly and moderately retarded people out of institutions into the community. Over the past 10 years, this movement has resulted in a 37% decline in the institutional population. At the same time, the residents who remain in institutions and those children and adults who have replaced some of the ones who moved into the community are far more retarded and multiply handicapped.

The number of severely and profoundly retarded persons in community-based facilities today is very small. The studies of how these people fare are few and inconclusive; and all the available evidence suggests that it is more a question of the way in which groups of individuals and staff are organized than the size of the residence. Pursuant to this concept, many of the larger institutions redesigned their larger wards into smaller units. Other factors such as geographical location, resident background, average age and the qualifications of the staff have been found to be more important in the development of the clients than the size of the facility.

The experience to date suggests that the concept that "bigness is bad" has no more truth when applied to the residences of the mentally retarded than it does to the size of corporations or universities. The experience to date would justify more experimentation with placing severely and profoundly retarded persons in community living arrangements, but it in no way would justify moving all such people into the community. What is needed is more experimentation and study; not more demagoguery. However appealing it is for people who do not have children in institutions to want to place our children in group homes with white picket fences, we the parents want proof-- empirical data, not articles of faith-- before we acquiesce in moving our children from environments in which they are doing well.

Existing Data on the Relative Costs of Institutions and Community Living Arrangements Are Contradictory and Inconclusive

The ARC has stated that cost studies demonstrate that for the same money we can serve two or three times as many mentally retarded persons in community living arrangements. Based in substantial part on this assumption, S. 2053 would increase the number of eligible recipients of Medicaid funds at least two to three hundred percent, and perhaps by as much as 700%.

Unfortunately, the cost studies do not support the basic premise. A fair reading of them shows that most are fatally flawed in conception. Many compare the costs of the typical resident of a group home-- a mildly to moderately retarded individual-- with the typical resident of an institution, a severely to profoundly retarded person. In addition, many of the studies do not compare the same constellation of services. In short, for every study that says that group homes are cheaper, there is one that says that institutions cost less.

Where similar residents and services are compared, the costs appear to be about the same. In Northern Virginia, for example, several intermediate care facilities for the mentally retarded-- which house 8 to 10 severely to profoundly retarded persons apiece, including some who have been discharged from the nearby institution--have found that their actual costs of care exceed the per diem costs at the institution.

The question of costs is an important issue. What is needed here is for proponents and opponents of the different living arrangements to sit down together and agree upon a proper methodology-- perhaps with some prodding and funding from the Congress-- and then hire an independent consultant to assess the real costs of caring for the severely and profoundly retarded in institutions and community living arrangements.

If S. 2053 Would "Guarantee" the Quality of Care for People Who Are Now Residents of Institutions, Why Are the Parents So Opposed?

Many parents fought long and hard to establish regional training centers so that their children could live in a quality residential environment close to them. Parents who have lived through all the difficulties and uncertainties of having handicapped children are particularly anxious to make sure their children will reside in a quality facility for the rest of their lives. To suggest that the certainty of good care that now exists will be replaced by an uncertain scheme is very threatening. In short, parents nationwide are pleased with the present situation and see no reason to trade it in for a system that at best might provide the same quality and at worst might have disastrous consequences.

Presently, our children live in places with substantial resources on hand--people experienced in how best to deal with a broad range of behavorial problems, including aggression, property destruction, self-injury, etc., and who are well grounded in current state-of-the-art technology, expertise not immediately available in a small community-based residential setting. In addition, our children have at hand the skilled services of physical and occupational therapists, social workers, doctors, nurses, dietitians, advocates and local human rights committees.

We have many questions about how our children would fare in community living arrangements. Would they have prompt access to all of these experts, or would they have to wait a week or a month until the experts could get to the house? We know how badly the local hospitals handle our children. Would there be small community facilities with doctors who understand their problems and needs? What would happen to people who have lived in institutions for decades? Is it really feasible to move them out without inflicting grievous harm?

What would happen to our kids when one of the staff was a bad apple?

Who else would be around to report that person? How would the facilities maintain the same kind of continuity that exists in institutions now when they had the kind of inevitable turnover that comes from burnout on the job and low financial rewards? Could Medicaid and other interested groups possibly monitor the quality of 20,000 community living arrangements as well as they presently monitor 260 institutions?

Finally, if group homes are to be opened up by definition to a potential universe of retarded citizens many times the size of those now receiving Medicaid funds-- with no criteria for choosing among applicants-- then the odds are great that many of our children will have no place to go when the states choose to close the institutions to save money. Or, if a state kept some of the institutions open, they would be far away from many of the parents and likely to be grossly underfunded. S. 2053 may say that any remaining institutions would have to maintain certain Medicaid standards, but when the financial crunch hits who is to say that those standards won't be reduced or laxly enforced?

Without criteria for admitting applicants into group homes, it is even possible that the bill might have the perverse effect of aiding mildly and moderately handicapped individuals to the detriment of the severely and profoundly retarded. This result could come to pass if states chose to serve the less retarded first in community living arrangements because they are less expensive to care for, i.e., they could serve more people for the same dollars.

We deeply empathize-- and we emphasize the word empathize-- with parents whose retarded children live at home. We have been there and we know how difficult it is. However, we know of no magic that can stretch the $3 billion in Medicaid funds being spent on the most retarded children living in institutions to provide services for three to seven times that population. The hard data simply isn't there to demonstrate that we can serve even one more retarded person and maintain the present level of quality care by moving the retarded into community living arrangements. The answer lies in more money and, until such time as the necessary funds are secured, a rational society always must devote its limited dollars to those people who are in the greatest need.

If S. 2053 Is Not Acceptable, What Can Be Done to Aid People Who Could Best Be Served in the Community, Whether They're Living in Institutions or at Home Presently?

The first answer is that more money is needed. There is no substitute for dollars. Realistically, with $200 billion deficits facing the federal government for as far as the eye can see, there is not likely to be much help forthcoming from the federal government. Therefore, the states may be the places to look. Many of their economies have picked up and the necessary monies would appear smaller on a state by-state basis. Moreover, it would avoid the potentially disastrous effects of imposing a national solution on the very different worlds that exist in different states.

Second, we must eliminate the bias in the Medicaid program that favors institutional funding. We believe the Congress made an impressive start in that direction with the Medicaid waiver program and we understand some 33 states have applied for waivers. That program should be expanded so that Medicaid funding is authorized for group homes on the same basis as it is for institutions.

Third, emphasis should be placed first on moving the mildly and moderate retarded, those without major physical or behavorial problems, out of the institutions and into group homes. These are the people everyone agrees are most capable of benefitting from living in the community.

Fourth, the role of the parents in caring for their children must continue to be respected. We love our kids and know more about them and what is best for them than all of the professionals in this field. Imagine how angry you would be if a teacher told you that you were raising your children incorrectly and that he or she-- the teacher-- was going to correct the problem.

And that teacher had the authority to do so. It is the height of arrogance and patronizing for people who are not in our situation to tell us that they know what is best for our children; that all we need to appreciate that they are correct is to be "educated."

Until there has been extensive experience in group homes with the many different kinds of children who are severely and profoundly retarded and that experience has been quantified and evaluated and truly shown to provide better care for all our children, we will continue to support federal funding for our institutions. We must maintain a continuum of services from private homes to group homes to institutions to assure that the particular needs of our children-- and not the needs of those with an ideological predisposition-- are best served.

STATEMENT OF EILEEN LeVASSEUR, BARRINGTON, R.I., MOTHER OF A RETARDED CHILD

Ms. LEVASSEUR. Gentlemen, my name is Eileen M. LeVasseur. I am almost 80 years of age, and among my several children is my daughter Marion, who is 45 years old and severely retarded and in a wheelchair.

Due to the lack of community support services at the time, plus the needs of my other children, I took action to place my daughter at the Ladd School in Exeter, R.I., in 1954. She lived there for 29 years until early 1983, when she was placed into a very nice group home with five other women, a few miles from my home.

I visited my daughter at least weekly during all of those years she lived in the institution, and, frankly, I was opposed to group home placement when it was first suggested as a possibility during 1978–79.

Most members of the Parents' Association of Ladd Center were likewise opposed to the concept, because no such community homes existed prior to 1980. I served as president of the Ladd School Parents' Association for 6 years, and my other daughter, who is with me today, has served as president for 4 years.

Today, all of us in the organization and all of my family are proud of Marion's new home. We support the idea of community residences completely, because we have seen with our own eyes how much better they are for our retarded children than the institutions we have known.

For this reason, we support Senator Chafee's bill, S. 2053.

Thank you.

This is my statement today. We have much more to say, but I guess we will have to wait for a later date. Thank you.

Senator CHAFEE. Well, thank you very much, Mrs. LeVasseur.

We have had some discussion here on the expenses, and Mr. Kinzler touched on that, and whether we are comparing apples and oranges; in other words, whether you take the cost of the group homes for say the mildly retarded, which can be relatively modest, compared to the expenses that would be involved for the severely retarded. And that is certainly a fair comment.

I think what we will try to do as we go along here is to seek further information on the expenses, because obviously that is a factor.

Now, another factor comes into play, and that is, if you implement the group home alternative you will certainly have a host of new patients or clients who will appear, who will chose being in the group homes. Well, I am not sure that is all bad. Yes, it might be more expensive; but, presumably, they are living with relatives or parents now, and for a variety of reasons they do not chose to institutionalize these "young people" because they have concerns about the institution but would be satisfied with the group home.

I don't think that means that every retarded child who is now being looked after by parents would necessarily go into a group home; I don't think that follows, although we don't know.

But, as I said in the beginning, the purpose of this exercise isn't solely a financial one, certainly not as far as I am concerned; it is to bring these clients or patients to their fullest potential. That is what we were seeking in the testimony we have had today.

We have a few minutes here, does anyone on the panel want to add anything? Briefly, now.

Mr. **Kinzler**. As briefly as you wish.

Senator Chafee, let me address what you were talking about. Senator Durenberger has kind of indicated in his statements that perhaps what he would be interested in is some kind of a voucher program. If you had enough funds available for all of the population we are talking about, you could more or less define what their needs were, give them a certain amount of funds, take off a certain amount for parents' participation, and then say, "Go choose." But you don't have enough funds. Your potential universe, the existing number of children in State institutions, appears to be approximately 138,000. How do you increase that universe twofold, threefold, or tenfold for the same dollars? I think the needs are there and they should be met, but I don't know how you do that. I think that is an exercise in magic; I don't know how to do it.

Senator **Chafee**. Well, as I get what you are saying, a voucher—namely, you could turn it in at a group home, you could turn it in at a St. Mary's, you could turn it in at the State training center.

Mr. **Kinzler**. Right.

Senator **Chafee**. And you are suggesting that if you did that you would have a host of new people appear who have up to date been looked after by their families. Is that what you are suggesting?

Mr. **Kinzler**. I think that all of the data suggested by Dr. Braddock and others indicates a much larger potential universe to be served. And using the eligibility criteria of your bill, it would be anywhere from 400,000 to 1 million or more.

Senator **Chafee**. Well, that may be. Somehow I don't think we want to save money by failing to meet needs. I mean, that's not exactly the way I want to proceed, and I am confident that is not the point you are making.

There are two points I want to make in conclusion:

One, I am convinced that there are savings in this. And it may be that it is the mildly retarded you are talking about. Well, why not? Let's proceed with that, and achieve the savings.

Second, I wouldn't want people to get involved in horror stories of what has taken place in A or B. And I know in the illustrations you gave you weren't suggesting that that is a reflection on group homes, that story about 16 in Florida. But I think we definitely don't want to start down on that path, because for every illustration one could find about something that has happened to somebody in a group home, you could counterbalance it with something that has happened to somebody in an institution. So it gets back to the care and the supervision, and we have got to advance on certain assumptions here, and that is that there is going to be decent supervision and care. And if there isn't decent supervision and care in the group home, there could just as easily be poor supervision in the group home.

So we know from experience—I am speaking from experience in my own State, where we have had great success, after proceeding very carefully, with the training of the personnel, and with careful selection and integration, and working with the parents, as Ms. LeVasseur has talked about that the community group homes can be extremely successful.

So, on those two particular points made by those in opposition to S. 2053: One, that it is going to lead to jerking patients out of a comfortable institutional setting and arbitrarily throwing them into a home—let's set that aside; that's not going to take place—and secondly, that there is lack of supervision in one or the other; I just don't want to start exchanging horror stories in that vein, because it is not fair, as we try to come to a fair and good conclusion of what is best for the patients.

Thank you, Mr. Chairman.

Senator **Durenberger**. Thank you.

Eileen, how old is your daughter?

Ms. **LeVasseur**. My daughter is 45 years of age.

Senator **Durenberger**. Forty-five?

I just want to tell one little story that I heard during the recess. This 45-year-old daughter went to the doctor to get her physical and see how she was, and the doctor said, "Oh, you're in great shape. You are going to live to be 100." So she came back to her 80-year-old mother and said, "Hey, I've got good news; I'm going to live to be 100." And her mother said, "What am I going to do with a 100-year-old daughter?" [Laughter.]

Ms. **LeVasseur**. I want to say something about Marion. Marion is so happy. There is a difference of day and night with her. She wouldn't be here today if she were still at the institution. That, I can guarantee you. She wouldn't be here today.

Senator **Durenberger**. Well, let me conclude by saying how please, as chairman of the subcommittee, I am that all of you are here today.

To go back to the focus of this hearing, for people who wanted to be witnesses today it looked like this was a hearing to say whether we were for or against S. 2053, I have concluded this is a hearing that is for the disabled in America, and for the improvement in their health care.

The question is: Now, that John has given us the leadership in moving in the right direction, how can we, in the larger focus that the subcommittee is working on for this year improve the quality of health care services by improving the way that we finance those services. How can we all come together on something that everybody here can agree on?

Really, it is not a matter, in this area, of wasting money. I just stepped out to take a phone call from my 16-year-old son who just went to the doctor. He came back with a 5-minute visit from the doctor, an X-ray, and a $95 bill. Well, I will tell you, there are some areas in this country where we are wasting money, it's coming out our ears. So we don't have the resources to do the really important things.

So, I don't feel that we ought to be constrained by the $8 billion or the $4 billion, or whatever it is, dollars and say, "There isn't enough to do this right," because there is so much in other parts of the system that we are absolutely wasting, that we shouldn't use that to beat up on health care for disabled persons.

So I will just conclude by thanking you.

Senator **Chafee**. I would like to thank all of the witneses on this panel, and the prior panels for the trouble they went to in coming here.

Senator **Durenberger**. Let us all thank John for his leadership in this effort. Thank you very much. [Applause.]

The hearing is adjourned.

[The prepared statements of Dr. Benjamin Ricci and Eileen Le Vaseur follow:]

[Whereupon, at 3:55 p.m., the hearing was concluded.]

Consolidated Testimony

presented by

Dr. Benjamin Ricci

for

The Massachusetts Coalition of Advocates for State Facilities

for the Retarded

before the

United States Senate Committee on Finance, Subcommittee on Health

Senator David Durenberger, Chairman

Monday, February 27, 1984

Until the decade of the 70s, for far too many of us, a choice of placement for our mentally retarded children was not available. Considering the fact that only five percent of the retarded was being served by the Commonwealth of Massachusetts, institutions had been made available to the "lucky" few. Some of the more fortunate parents/guardians/relatives, i.e., the politically connected, had been given placement opportunities in other states. But for the majority of us, it had to be institutions in Massachusetts, misnamed "state schools" for the retarded.

It is well to emphasize that there was no choice of placement.

Without question, for the overwhelming majority of us, the decision to institutionalize our flesh and blood was the most difficult, heart-rending decision we have ever had to make and perhaps will ever have to make. But for a variety of soul-searching reasons, many of us took the step in order to preserve our individual and collective (family) sanity and to provide opportunity for normal growth.

Through the years, for many of us, the institutions became increasingly harder to bear. State schools were finally seen in their true light: they were colossal misnomers. Civil rights were stripped from our institutionalized children, as were the protections afforded by the First, Fifth, Eighth, Thirteenth, and Fourteenth Amendments to the Constitution of the United States of America. Some of us realized that America had let us down. We filed class action suits in the Federal Court. Robert Simpson Ricci et alii v. Milton Greenblatt et alii,[1] filed on February 7, 1972, was both historic and precedent-setting in Massachusetts and America. As a result of Federal Court prodding and guiding, the Commonwealth of Massachusetts, in particular, made improvements. "Human warehouses" and "pig pens" were gradually transformed into places which, given the will to do so and the proper leadership, could easily become residential centers and fully deserving of praise.

Also as a result of our insistence and constant prodding, community programs were set up as part of the consent decree process. But as the record reveals, the community programs were set up neither to humanize nor recognize the dignity and worth of retarded persons but merely to deinstitutionalize. Deinstitutionalization, that ugly word and concept which reveals its negative self by the prefix de merely directed defendants to take away from, to reduce the populations at the state schools.

My record of advocacy (now more than fifteen years), my membership on a Special Legislative Commission which investigated two of five Massachusetts institutions for the mentally retarded, my status as "father and next friend", in legal terms, of the principal plaintiff in our historic class action suit filed more than twelve years ago in the United States District court in Boston, and my having lived with the problem for close to thirty-seven years qualifies me as an expert on mental retardation, especially in Massachusetts.

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[1] 72-469-T. Other related cases are identified as: 74-2768-T, 75-3910-T, 75-5023-T, and 75-5210-T.

Furthermore, my academic preparation and my one-third of a century experience as a biological scientist on the University of Massachusetts/Amherst faculty has been of immeasurable benefit, especially when dealing with the issue of the administration of psychotropic medications and the resulting side effects among the mentally retarded; the deleterious effect of poor diet and lack of exercise; and the contribution of noice, ambient, and heat stresses on the mentally retarded.

In my travels throughout America I have learned from the social scientists and those employed in the social services that Massachusetts is viewed as a "leader"; is "light years ahead in its thinking and in its implementing of programs for the developmentally disabled" ; is "the place to be for professional excitement"; and has always been at "the cutting edge of change." I remain unconvinced by such kudos because the Massachusetts I know leaves much to be desired. Of course, those kudos might be considered in a relative sense, but if that is the case, then America, in fact, is in need of a fundamental overhaul of its ways and thinking about care and services for its mentally retarded population.

My succeeding remarks will be applicable to Massachusetts. By way of a preamble, it is interesting for me to note that major support for passage of S.2053 comes from the Association for Retarded Citizens, United States, (ARC/US) a.k.a. NARC, whose former president, Mr. Joseph Bunonomo, has long been active in the Massachusetts ARC (MARC), as well as from other MARC members who have been extremely vocal in supporting S.2053. It is safe to say that this bill has been advanced by MARC's efforts, an association which very seldom played its advocacy role but has steadily increased its service-provider role. In an economic sense, so effective has MARC become as a vendor of services that today it is a business: as a collection of vendor ARCs, it receives more than eleven million dollars out of approximately fifty million dollars awarded by the Commonwealth of Massachusetts for services. It is merely good business sense for MARC and ARC/US to lobby vigorously for passage of S.2053. Some years ago we recall hearing Mr. Charles "Engine Charlie" Wilson insist that what was good for General Motors was good for America. Many of us rejected that audacious remark. Likewise, we reject the view that what is good for MARC and ARC/US is good for retarded persons and their parents/guardians/relatives.

It is well also to expose the false assumption that ARC/US and MARC speak for all retarded persons and their parents. I wish to state emphatically that they do not speak for the Massachusetts Coalition of Advocates for State Facilities for the Retarded, the largest, most active, true advocacy group in Massachusetts. This coalition, representing parents/guardians/relatives of residents of all the institutions in Massachusetts, is shocked at the limited position taken by ARC/US and MARC. This position simply does not meet needs and wants nor is in the best interest of all retarded citizens. To phrase it another way, ARC/US and MARC speak for the Massachusetts Coalition as legitimately as Yasser Arafat speaks for all the semites.

Let us now turn to some assumptions upon which S.2053 is based. After all, an assumption means "to pretend to have", "to suppose as a fact--without proof."

First False Assumption: Generic medical, dental, health, and therapeutic services are in place and available in community settings, as presumed in S.2053.

The generic services described above do exist at institutions and were gained as a result of the class action suits cited earlier.

Second False Assumption: All placements made, especially since the involvement of the federal court, were based on the individual needs and wants of retarded persons who were "freed" from institutions.

As recently as two weeks ago, a motion was filed in U.S. District Court in Boston in Ricci to return to Belchertown State School, two hundred thirty-three class members who currently reside in nursing homes without benefit of active treatment, effective programming, and individual service plans (ISPs). The number of class members in Ricci and related cases who were placed in nursing homes approximates one thousand. Those persons were literally delivered, like objects, to nursing homes in the hey-day of deinstitutionalization with full verbal assurances given by then Mental Health Commissioner, Robert Okin, that they would be treated with "full dignity and respect" and would "develop" due to the "exposure to stimulating programming." U.S. District Court Monitor, Anne Berry, expressed the plaintiffs' collective view. "Many of these clients [in nursing homes] placed in the early days of the consent decree in an effort to get the census level down (emphasis mine) now sit in nursing homes where, once again, they have the potential of being the victims of neglect, at the least, and abuse at the worst, and in those situations these people do not have day programs."[2]

Third False Assumption: Well-designed, organized, financed, administered, and functioning community-based programs and facilities currently exist.

As a result of our monitoring of community-based facilities for class members in Ricci and related cases, we have seen the complete absence of the above cited qualities.

In fact, we have observed many under-served class members whose ISPs have been deliberately "written down", i.e., they contain deliberate, glaring omissions in order to keep costs down. We have also identified many unserved class members.

In fact we have observed many mini-institutional models which stifle personal growth and development.

All this has happened despite the rhetoric that "Massachusetts, especially Western Massachusetts, has the most extensive and best examples of community residences in the United States."

Fourth False Assumption: A "plan" exists which will "accommodate" 480 persons currently residing in state schools into community residences during the forthcoming fiscal year.

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[2] Transcript, Robert Simpson Ricci et alii v. Milton Greenblatt et alii Civil Action 72-469-T, and related cases, U.S. District Court, Boston, January 29, 1981, p. 73.

This "plan", billed during former Governor Edward King's administration as the "Expanded Phase-Out Plan", was thoroughly discredited in the Federal Court by U.S. District Judge Joseph L. Tauro, as well as by numerous plaintiffs. Especially noteworthy is Judge Tauro's remark, "I want you to understand that I've been listening to this community placement projection, these projections, for seven years now and that will be it."[3]

The recently deceased Secretary of Human Services, Manuel Carballo, said during a meeting on January 20, 1984 in the presence of Governor Michael Dukakis, plaintiff representatives, plaintiffs' attorney Beryl Cohen, and high administration officials including Commissioner of Mental Health James Callahan that "the projection of 480 persons is unrealistic; it cannot be accomplished."

In truth the Commonwealth of Massachusetts has never lived up to its projections over the past twelve years, hence the current back-log and the resulting problems.

Despite the written agreement contained in the Capitol Community Plan portion of the Consent Decree, introduced in 1977, the defendants have failed repeatedly to establish a workable, quality plan. In this regard, U. S. District Court Monitor Anne Berry stated, "A major concern of the plaintiffs regarding the establishment of the community system is that, once established it be maintained and improved, as necessary, and when a problem is detected it be addressed." Each plaintiff group has raised this repeatedly."[4]

Motions have been filed to close down two state operated residential programs (SORP) because they violate the provisions of the Consent Decree in Ricci. They were in reality scenes from "One Flew Over The Cuckoo's Nest." Other similar motions, relating to vendor operated programs are soon to follow because the vendors are experiencing "financial difficulties."

Fifth False Assumption: Community residences are less expensive to operate.

Given the current state of affairs, per capita costs are less, but this is due to vendors' agreeing to shoestring operations which has resulted in high, staff-burnout, and an "82% state-wide staff turnover rate" (which has a noticeable impact on retarded persons exposed to frequent staff turnovers), and staff-pay differentials on the order of $3,000 per year less, in addition to lack of employment benefits.

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[3] Transcript, Robert Simpson Ricci et alii v. Milton Greenblatt et alii, Civil Action 72-469-T, and related cases, U. S. District Court, Boston, January 29, 1981, p. 106.

[4] Ibid., p. 73.

Quality community residences and programming have been shown to be costly to the extent that they exceed institutional per capita costs. Once again, to quote the late Human Services Secretary Manuel Carballo, "In most states, deinstitutionalization was sold as something that would cost less. It's now clear that good community care is expensive. There is little difference in cost from institutional care."[5]

Sixth False Assumption: Community residences, with qualified staff and generic services, currently exist to serve those who are profoundly retarded and who possess multiple handicaps.

In fact, the only certain way for residents to leave buildings E, F, and the Infirmary at Belchertown State School and similar residential buildings at the other state schools is in a hearse. Their dilemma and the plaintiffs' frustrations is compounded by the fact that through the years vendors have repeatedly refused to serve this population. This is true on a state-wide basis.

Seventh False Assumption: Institutions are inherently bad and, by contrast, community residences are inherently good.

Given the bias resulting from prejudice and an ignorance of the working models of successful residential centers such as those in Scandinavia (in contrast to our institutions), mental health administrators and middle management personnel repeat parrot-like their disdain for institutions. I have toured Scandinavia extensively, was impressed, and remain so. The Scandinavians continue to lead us by light years.

Institutions can be improved operationally as well as physically, by hiring administrators and middle management personnel who are faithful to the concept of and, of course, understand the steps needed to transform institutions into residential centers. This would also afford parents/guardians/relatives the freedom of choice. There is a need for both institutions and community-based residences. A choice must be available to parents/guardians/relatives.

I note with interest that Press Release No. 84-106, announcing the hearing on S.2053, the Community and Family Living Amendments of 1983, reveals an anti-institution bias, as well as an assumption of costlier institutional care. The anti-institution bias is held and espoused by those persons whose professional preparation was deficient. Those persons are being driven by an impersonal guidance system, much as a missile is targeted. They navigate by ideology rather than reality, to paraphrase columnist George Will, and they remain closed to evidence. They are social scientists in name only, not bothering to examine the data.

Institutional versus community-care costs reveal the disgusting deception they practice. If cost calculations are made both carefully and honestly, they reveal, as they do in Massachusetts, that offering quality care, programming, and residences in stable, desirable neighborhoods results in per capita costs which are approximately equal for institutional and community care.

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[5] "State school funds won't end debate $97.5m in improvements doesn't address future of institutions for the retarded", The Boston Globe, Jean Dietz, December 25, 1983, p. 22.

Many of us have advanced this argument for years; however, the biased, human services (including mental retardation) administrators assiduously avoid calculating true costs for services. The only high administration official to recognize this and courageously express it in a candidly refreshing way was the late Human Services Secretary Manuel Carballo.

An examination of per capita costs which reflect lower community-delivered service costs traditionally reveals: (1) Deliberate omissions of programming and services which would enhance the personal growth and development as well as the humanization of the retarded consumer. (2) Deliberate omissions of the costs of service-provider agencies and service coordinator agencies. (3) The salaries of professional and technical staff persons who are assigned to community based programs, but are carried on the books of institutional budgets, hence incorrectly inflating institutional costs while deflating community-setting costs. (4) The considerably lower salaries of non-profit operated programs resulting in excessively high turn-over rates, viz, 82% in Massachusetts.

For the sake of intellectual honesty, I urge the recalculation of costs by impartial accountants in order to put this matter to rest. It is obvious that the continued repetition of facts or figures irrespective of correctness, ultimately assures a measure of validity and truth. With license to paraphrase, "figures don't lie but [biased persons] do figure." The enlightened American society deserves this recalculation, thus making it necessary.

I note with interest a recent reply by U.S. Senator John Chaffee, sponsor of S.2053, to one of his constituents who expressed concern and opposition to S.2053. Predictably, Senator Chaffee proclaimed, "Rhode Island is the most advanced state in the country in providing community-based services." From that, it is obvious that such political proclamations do not require a hard-data base, for if one were available I suspect that statement could not have been made. Secondly, continued the senator, "one of the key sections of S.2053 is an assessment of each individual's needs--the parents are participants in that assessment." It is obvious the senator dutifully signed a letter composed by a biased staff person, or by a professional mental retardation administrator, or social worker. In the real world, parents recognize how hopelessly outnumbered--and badgered--they are. Furthermore, it is revealing that "needs" or biological necessities are to be assessed, but no mention is made of wants, those quality of life, psychological, religious, sociological considerations.

Most glaring of all in Senator Chaffee's letter is the omission of total cost of this package. Continuing to be unserved are those retarded persons who are not class members (in Massachusetts) or those who have never been at Rhode Island's Ladd School or who were fortunate not to have been improperly placed at the state mental hospital in Howard, Rhode Island.

Men can never fully comprehend the experience of childbirth. There is no retort to such a biological truism. It is equally obvious that persons who have not contributed biologically to the creation of a mentally retarded child can never fully comprehend the tensions, frustrations, sorrows, and emotional drains associated with mental retardation. Stress is relentless; no single day is ever completely free from it. Concern is ever present; respites may involve only hours, seldom days, never weeks.

It is clear that S.2053 was crafted by professionals who navigate by ideology rather than reality. They were aided by others whose sole purpose was to protect business enterprises. What is obviously lacking is input from parents and families who have experienced the relentless stresses associated with their retarded family members.

Parents are articulate, visionary, advocates in the truest sense of the word, and are extremely capable of contributing inputs which would have affected any proposed legislation such as S.2053. We not only do not require ideologue spokespersons, we do not wish their intrusions, their insensitivities, their mistaken belief that increased chronological age among the mentally retarded brings with it presumed competence. We are outraged at their charge that we are overprotective, when we merely believe that putting retarded persons into society without well conceived support systems is both morally offensive and a repugnant violation of human dignity.

Perhaps it would surprise the reader at this time to learn that my son, Robert Simpson Ricci, resides in a staffed apartment in Amherst, Massachusetts. He is employed by the Town of Amherst. Our community of Amherst is as ideal and supportive an any in America. Those gains, however, were the result of constant vigilance and abundant persistence to force state government to do its job better. They came neither easily nor predictably. But, they came.

For the Riccis, a choice was finally offered. However, it came after more than a decade of vigorous advocacy. Yet, there are parents/guardians/relatives who believe, as do I, that the right to choose between institutional and community settings is fundamentally and thoroughly American. It is important, for those persons in particular, but also for all of us in general, to have their wishes respected especially their wish that their children be served in what is currently called an institution. In Massachusetts, because of our collective advocacy and because the U.S. District Court is an effective forum, institutions are places where excellent medical, dental, therapeutic, and vocational services are offered; where staffing has improved, and environments have been drastically upgraded. So the choice should belong to parents/guardians/relatives. They must not be forced to accede to the wishes of ideologues.

S.2053, as it is currently written, does not allow for choice. If passed, it will dictate community living, because it will eliminate state schools over a specified time frame. The freedom to choose is an American right. Would our Congress take away our freedom to select private schools over public schools?

S.2053 lacks much of substance. Any future bill must be distinguishable by the provision for ombudsmen, roles to be filled specifically by biological parents of retarded persons, chosen for their independence, vision, courage, and their sensitivity to wants and needs of retarded persons. This would most likely assure quality control, thus enabling retarded persons to grow and become humanized.

TESTIMONY TO THE U.S. SENATE COMMITTEE ON FINANCE

Re: S.2053

Filed with: Roderick A. DeArment, Esquire

Submitted by:

Mrs. Eileen LeVasseur
Past President
Parents' Association of Ladd Center (P.A.L.)
253 Narragansett Avenue
Barrington, Rhode Island 02806

February 22, 1984

SUMMARY

This testimony is in support of S.2053, given from the perspective of a parent of a severely disabled retarded daughter and representing an organization of parents of persons with retardation in an institution.

My name is Eileen M. LeVasseur. I am almost 80 years old, and among my several children is my daughter, Marion, who is a 45 year old severely retarded woman in a wheelchair.

Due to the lack of community support services at the time, plus the needs of my other children, I took action to place my daughter at the Ladd School in Exeter, Rhode Island in 1954. She lived there for 29 years, until early 1983, when she was placed into a very nice group home with five other women a few miles from my home.

I visited my daughter at least weekly during all of those years she lived at the institution. And, frankly, I was opposed to group home placement when it was first suggested as a possibility during 1978-79. Most members of the Parents' Association of Ladd Center (P.A.L.) were likewise opposed to the concept because no such community homes existed prior to 1980. I served as the President of P.A.L. for six years, and my other daughter has served as President for four years.

Today, all of us in the organization and all of my family are proud of Marion's new home. We support the idea of community residences completely, because we have seen with our own eyes how much better they are for our retarded children than the institutions we have known.

For this reason, we support Senator Chafee's bill, S.2053.

Thank you.

SUMMARY OF MAJOR POINTS OF TESTIMONY
by Karen Green-McGowan, R.N., before
UNITED STATES SENATE COMMITTEE ON FINANCE
Subcommittee on Health
February 27, 1984

MAJOR POINTS

1. Health services to institutionalized citizens are almost universally substandard. Access to health care services available to the ordinary citizen is vastly superior.
2. Institutional environments are more hazardous than community settings.
3. Persons with complex medical needs are particularly vulnerable to the effects of trauma and infection and the "revolving door personnel" phenomena in congregate care settings.
4. The most consistent commonality shared by the profoundly handicapped, medically fragile population is the diversity of their needs. Complex needs are compounded in complex environments.
5. The more handicapped the person, the smaller the setting should be.

In the nearly twenty years since I began working with the persons labelled "multi-handicapped", "medically fragile" and usually profoundly handicapped as well, I have observed the response of these persons in nearly 70 institutional settings in North America. I have had the opportunity to work with catastrophically handicapped children and adults during their transition from large state or provincially operated facilities to small, dispersed community settings in 17 states and 7 Canadian provinces during the last 12 years. In many cases, I have maintained a 3-5 year running contact with those persons in their new community lives. I can tell you that almost without exception the worst community setting is better than the best institution I have seen.

My initial seven years in the field were spent first as a Nurse clinician and then as a program administrator for 240 multiply handicapped persons ranging in age from almost newborn to mature adulthood. We were so concerned about preventing hepatitis and boils in our population in 1965 that little staff effort was left to get people off their backs. We had no equipment to get them out of their beds. A good staff ratio then was 1:20.

Things have changed a lot in the succeeding 20 years, and there are more resources now to assist neurologically impaired children and adults. But, as I wander from institution to institution whose annual fiscal expenditures are simply staggering, I have long been puzzled to answer why these facilities fail to achieve the humanization and developmental progress I see in their deinstitutionalized (or never institutionalized) twins who live in homes or very small groups, usually at a fraction of the cost of institutional care.

This phenomena certainly has little to do with the caring or concern of the staff who interact with them on a daily basis. I have yet to train or consult in an institutional facility where the majority of staff did not urgently desire what was best for their clients. Interestingly enough, what most hands-on personnel want for those incredibly handicapped persons in their care is to get them out of the institution and into a home. In 1969 at the institution in Glenwood, Iowa where I worked, we shipped 30-40 severely handicapped young children home with our direct service staff each weekend. Although unorthodox and frowned upon by top administration, we were determined that our youngest children would not suffer the effects of congregate living and deprivation of family life that dulled the souls of our older residents.

In the area of acquiring health care, we were not so fortunate:

> "There appears to be general agreement that the quality of health services available to most of our institutionalized handicapped children is substandard when compared to that available in the general community. The residents of institutional facilities, for whom the option to choose their doctors or types of health care given is not available, are generally required to live in an environment containing more hazards to health through infection, trauma or other causes than exist in the average community setting."[1]

In our case, children and adults with major, acquired deformities were consistently refused corrective surgery that would allow them to sit, move, or develop because they were confined to "custodial care" in an institution and perceived by health care providers as waiting to die. This was compounded by apathy on the part of our facility physicians, many of whom were out of touch with current medical practice.

Persons with damage to the motor centers of the brain, as in cerebral palsy, must depend on others to assist them in achieving normal movement. Early intervention now prevents a significant percentage of the disability seen in older populations deprived of preventative care. This is now being delivered by therapists using family members as primary intervenors. What counts most for these current youngsters is that one or two persons, usually their parents, are carefully and systematically trained by developmental therapists to handle them in ways that encourage normal movement to to develop and prevent the deformity that inevitably results when severely handicapped children are left on their backs.

Contrast the response when children are ripped from their families, placed in impersonal settings and handled by ever-increasing numbers of marginally trained persons who leave on a regular basis without saying good-bye. In one facility in Kentucky whose ward for 16 multi-handicapped persons met AC/MRDD ratios, but had a 190% turnover per year, 56 different persons laid their hands on every client in a 12 month period. It is not difficult to imagine the fear and anxiety a child might experience under these not uncommon conditions when every movement transition is dependent on the hands of another. Some jerk, some yank by arms and legs in ways that cause fractures. But everybody seems to go away sooner or later.

What is important to understand about this population labelled medically fragile is that their most consistent commonality is the diversity of their needs. In the days when we believed that persons with severe handicaps needed only to be kept clean and comfortable, a nursing care or medical management model seemed quite appropriate. What is interesting to discover when incredibly handicapped kids are given conditions experienced by their non-handicapped peers, is how much they can achieve, even when that chance is given late in life. There is a program in Kentucky called "New Neighbors" where severely handicapped children and adults are brought back to family settings, one per household. They began to move, creep, crawl, walk and talk at incredible speed. When they need medical care, they get it from community physicians. If they don't get what they need, they go elsewhere, or their host families push, prod, nudge and harangue until these individuals get what they need. The cost: one fourth of the institutional per diem. In two cases, children returned to their own homes. Had fiscal support been available, more could have been reunited with their families.

This is only one example of a growing trend toward supporting persons with complex needs in single placements in family settings where they tend to thrive and rapidly become less complex.

I am currently involved in a special project in Florida, which will close its last facility serving medically complex persons by the end of 1984. These very complex clients are all moving into 4 bedroom houses located in their home communities all over the state. The death rate for the majority of this population that has lived in community for the past two years has been less than half that of the two institutions from which they came.

When I look back over my last twenty years with this population both in the institution and in the community, I am left with the following conclusions:

1. Health services to institutionalized citizens are almost universally substandard. Access to health care services available to the ordinary citizen is vastly superior.
2. Institutional environments are more hazardous than community settings.
3. Persons with complex medical needs are particularly vulnerable to the effects of trauma and infection and the "revolving door personnel" phenomena in congregate care settings.
4. The most consistent commonality shared by the profoundly handicapped, medically fragile population is the diversity of their needs. Complex needs are compounded in complex environments.
5. The more handicapped the person, the smaller the setting should be.

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[By direction of the chairman the following communications were made a part of the hearing record:]

TESTIMONY OF BETHESDA LUTHERAN HOME ON S. 2053, THE COMMUNITY AND FAMILY LIVING AMENDMENTS ACT OF 1983, BEFORE THE SUBCOMMITTEE ON HEALTH OF THE SENATE COMMITTEE ON FINANCE

My name is Alexander L. Napolitano. I am Executive Director of Bethesda Lutheran Home located at 700 Hoffman Drive, Watertown, Wisconsin 53094. I would like to thank the Subcommittee for this opportunity to offer Bethesda's views on S. 2053, the Community and Family Living Amendments Act of 1983. Quite simply, Bethesda believes that S. 2053 would disserve the Nation's retarded citizens.

I. BETHESDA'S MISSION.

Bethesda is a private, non-profit organization serving nearly 450 retarded people from 31 states and one foreign country on its main campus in Watertown, Wisconsin. Bethesda's residents range in age from 8 to over 90. Bethesda also presently operates 10 group homes in 8 states and has 3 more such homes under development. The overall capacity of these group homes is 103 beds.

Bethesda has been successfully serving mentally retarded children and adults since 1904. Starting as a small facility for a few retarded children, Bethesda has grown to be a nationally recognized and widely respected home and training center for retarded persons. Located on nearly 500 acres of land in a pastoral setting bordering the Rock River, Bethesda residents are cared for by a staff of nearly 600 people. Moreover, over 5,000 volunteers help to enhance this care. The Watertown main campus includes dormitories, a vocational workshop, therapy rooms, an infirmary, detached small group homes, an educational center, a chapel, service buildings (for printing, maintenance and laundry) and extensive recreational facilities (gym, swimming pool, arts and crafts).

Bethesda also conducts workshops to train people to work with retarded persons, publishes various educational materials and strives to develop public awareness of the needs of America's retarded citizens. Bethesda provides respite care (short-term care for a retarded person while the family enjoys a vacation or deals with an emergency) and intends to open a Christian Resource Center and a Diagnostic and Evaluation Center to provide information and guidance to families of retarded persons and to the parishes that serve them.

When Bethesda was founded in 1904, little was being done for retarded people. Often they were ignored, mistreated, hidden in back bedrooms or jailed as criminals. For the last 80 years, Bethesda has been a pioneer in working to change these misconceived stereotypes and in training retarded individuals to develop productive skills.

Bethesda's success in serving mentally retarded citizens has been widely acclaimed. A study funded by the Joseph P.

Kennedy, Jr. Foundation and conducted by Dr. David F. Allen at the Harvard School of Public Health, found Bethesda's programs to be exemplary.* State inspectors have praised Bethesda's institutional programs and have concluded that its group homes are models of the group home concept. Indeed, Bethesda's work received national recognition in the NBC Television documentary entitled "No Miracle But Love."

Bethesda is deeply committed to the concept of permitting retarded persons to live as normally as possible with as much autonomy over their own lives as their capabilities allow. To that end, since 1975, Bethesda has moved 260 residents to group homes, supervised apartments, foster care placements or back to living with their natural families.

To ease the transition away from Bethesda and to make as rewarding as possible the lives of those residents who most likely can never live in the larger community, Bethesda provides extensive habilitation programs. These programs include educational and vocational training; religious instruction; social, medical, nursing and psychological services; behavioral training; and occupational, physical, speech, recreation and music therapies.

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* The results of that study are published in a book by Dr. Allen, now Assistant Professor of Psychiatry at Yale University, and his wife, Victoria, entitled Ethical Issues in Mental Retardation: Tragic Choices/Living Hope (Abingdon 1979) with a foreword by Eunice Kennedy Shriver.

II. S. 2053 WOULD DISSERVE THE INTERESTS OF AMERICA'S RETARDED CITIZENS.

Bethesda's 80 years of experience in caring for retarded citizens demonstrates that many retarded people progress much faster when they have regular access to the intensive therapies, medical services and educational and job training programs which can only be made available at a large institution. S. 2053 would phase out federal funding to institutions for mentally retarded people and, instead, provide federal funding for small group homes. With their federal funding gone, institutions for mentally retarded persons would have to close. As an operator of both a large institutional facility and a number of small group homes, Bethesda opposes the doctrinaire bias of S. 2053 against institutions for mentally retarded individuals.

A. Summary of Bethesda's Position.

Bethesda opposes S. 2053 for the following reasons:

1. S. 2053 would have the effect of closing all institutions for mentally retarded persons, including private institutions such as Bethesda.

2. S. 2053 assumes, without basis, that institutional care is universally inferior to small group care for all retarded citizens.

3. S. 2053 incorrectly assumes that community placement is always the least restrictive alternative even for severely and profoundly retarded people.

4. S. 2053 would make it much more difficult for retarded citizens to exercise their religious freedom.

5. S. 2053 assumes, without basis, that the cost of implementing group home care for retarded people would be less than institutional care.

6. S. 2053 does not take into account the failures nor prevent repetition of the abuses which have resulted from previous deinstitutionalization programs.

7. S. 2053 ignores the effect of deinstitutionalization on the families of retarded persons, on staff members who care for retarded people, and on the community at large.

8. S. 2053 is not a necessary prerequisite to the development of group home care.

B. Total Deinstitutionalization Would Disserve Many Retarded Citizens.

1. S. 2053 Would Have the Effect of Closing All Institutions for Mentally Retarded Persons, Including Private Institutions Such As Bethesda, In Favor of Group Homes.

The goal of S. 2053 is to deinstitutionalize mentally retarded individuals. To that end S. 2053, over a period of ten years, would eliminate all federal funding for institutions for mentally retarded persons in favor of funding for "community or family living facilities." Such facilities would be limited to caring for a group of people no more than three times the average size family household in its area. In short, small group homes would be federally funded but larger facilities would not.

Because of the extensive services and staffing ratios mandated by law (which Bethesda believes to be both appropriate and necessary), no facility can operate today without the funding assistance its residents receive from Medicaid. While about half of Bethesda's 1983 operating budget came from contributions from over 200,000 people living in every state in the Nation as well as income from its investments, the remainder of Bethesda's operating budget came from the Medicaid moneys which S. 2053 proposes to eliminate.

It is unrealistic to believe private funding sources could cover the $7,355,000 portion of Bethesda's operating budget which Medicaid funded in 1983. Nor is it realistic to count on income from endowment funding. At current interest rates, Bethesda's endowment would have to increase by $70-80 million to provide enough income to cover the loss of Medicaid funding. It is also unreasonable to expect the states to assume the funding responsibilities now borne by Medicaid, especially for private institutions with residents who come from many different states across the Nation.

Thus, there is no doubt that an elimination of Medicaid moneys would eventually close Bethesda as well as all other facilities larger than the small group homes to be funded under S. 2053. By so doing, S. 2053 eliminates freedom of choice. Retarded citizens should have the choice of a home in the community or in an institution, depending on which setting best meets a particular individual's needs. The federal government should not employ its power of the purse to enforce one model of care to the exclusion of the other.

2. S. 2053 Assumes, Without Basis, That Institutional Care is Universally Inferior to Small Group Care for All Retarded Citizens.

Bethesda does not oppose the general concept of deinstitutionalization. Indeed, Bethesda has been at the forefront in returning its residents to the community and in establishing group homes. But while deinstitutionalization is the best course for _many_ retarded people, it simply is not a solution for _all_ retarded people.

Bethesda's experience with group homes demonstrates that such facilities are good for moderately retarded individuals who can function independently in society while living with peers in a protected environment. But for severely and profoundly retarded individuals group homes are usually not the answer. These individuals do not do well in small group homes because they are often non-verbal and are unable to communicate their problems or to perform such basic skills as bathing, dressing and cooking. As Dr. Arthur Mayer concluded in his October 21, 1983, report to the California ARC:

> "What may be optimal in small communities may not necessarily be optimal in our crime-ridden, traffic-congested, impersonal, modern cities. Similarly, what may be optimal for mildly and moderately retarded individuals, who can relatively easily communicate and intermix with the neighboring community, may not necessarily be optimal for profoundly and severely retarded people, whose needs and capabilities are vastly different."

It would be nothing short of a tragedy if the Subcommittee were to ignore this reality.

Bethesda believes that the laws in place today to eliminate inferior institutions should be strictly enforced to prevent the past abuses which occurred in some institutions for mentally retarded persons. But government intervention should only ensure the quality of care; it should not remove institutions as a choice for those who are retarded. Exemplary institutions provide exemplary care.

A fair inquiry into the institutional reform movement in mental retardation demonstrates the invalidity of the assumption that smaller facility size means better quality care. For example, James S. Payne and James R. Patton, in their treatise Mental Retardation (Charles E. Merrill 1981) at pp. 314-15, concluded that "it is incorrect to presume a retarded person will be better served in a smaller facility simply because it is smaller."

Moreover, Sharon Landesman-Dwyer of the University of Wisconsin, conducted a study in 1981 in an attempt to isolate causative elements which contribute to a retarded person's successful living in the community. Landesman-Dwyer concluded that, while many unfortunate living situations existed in large institutions, the size of a facility, as such, does not have any material adverse effect on a retarded person's living experience. Rather, the appropriate facility for a particular individual is dependent on the resident's age, past experience, ability level and current life situation.

As a result, Landesman-Dwyer rejected precisely the doctrinaire solution to care for the mentally retarded which is the animating force behind S. 2053 (cited in a Report by Arthur Mayer, Ph.D, to the Association of Retarded Citizens -- California Medicaid Restructuring Forum on October 21, 1983):

> "Indiscriminate solutions, such as small family-style homes for everyone, will not long prove satisfactory. Indeed, some such well intentioned social policies already have failed or led to backlash." (Emphasis supplied).

3. S. 2053 Incorrectly Assumes That Community Placement Is Always the Least Restrictive Alternative Even for Severely and Profoundly Retarded People.

Community placement is not the least restrictive placement for many severely and profoundly retarded persons. For example, a large institution provides a better living situation than would a group home for people who need major medical/nursing support systems, who are not ambulatory, or who cannot consistently follow even the simplest of instructions. Such people may never be in a position to live in group homes -- certainly not in two years as implied by S. 2053 or in the foreseeable future (S. 2053, Section 1918(b)(3)).

For many of these individuals an institutional setting provides more rather than less personal freedom. For severely retarded persons, with short attention spans and limited abilities, a large institution such as Bethesda provides the concentration of staff and frequency of services which lower-level retarded persons need. At Bethesda, those who might be confined to their bed elsewhere are taken to classes, to meals and to special events. They are not confined to one or two rooms as they would be in a small facility. Moreover, when services are miles away, time is consumed in travel to the therapy site which can necessitate shortened therapy programs.

In their book, Payne and Patton emphasize that, as a general matter, the institutional setting has value and often is the least restrictive alternative for severely and profoundly retarded citizens (id.):

> "Many people now recovering from years of rampant anti-institutionalism inspired by various court cases have begun to realize that residential services indeed may be appropriate for those severely and profoundly handicapped persons for whom community placement is far from 'least restrictive.'"

Payne and Patton point out nine benefits of the institutional setting, all of which have been borne out by Bethesda's experience.

a. "A concentration of mental retardation specialists and medical personnel."

Bethesda has a full-time medical director and over 50 nurses; dozens of teachers and teachers aides, supported by psychological and psychiatric consultants, all trained in mental retardation; extensive in-service training for all direct care staff, plus scholarship assistance to assure that staff remains professionally current.

b. "A setting where necessary medical and technological support can be housed most economically."

Bethesda's costs average between \$66 and \$73 per day per person (we receive only \$49 per day for those on Medicaid) while costs at state facilities are over \$100 per day. Providing the level of care offered at Bethesda in a facility of 15 beds or less for severely and profoundly retarded individuals would not be economically feasible.

c. "A structured and systematic life-style, which severely and profoundly retarded persons usually require."

Bethesda has found that routine is absolutely essential for lower-level retarded persons. Only after years of training are most seriously retarded persons able to enjoy a less restrictive environment.

d. "A 'home' among peers characterized by individual attention and care, in contrast to the mainstream community where retarded people generally bring up the rear."

We all need to experience success. There is no way, however, that severely retarded persons can "win" in competition with "normal" people. At Bethesda, through quarterly case reviews and through special activities, we structure opportunities for personal success and accomplishment. If a resident has not been meeting program goals, these goals are broken down into smaller goals which can be mastered, and praise and rewards are given for mastering each step.

e. "A location where qualitatively sound and ethically sanctioned research -- both pure and applied -- can take place; accomplished by encouraging in-house staff who demonstrate the requisite research skills, interests and by cooperating on joint ventures with universities and other research groups."

Before Bethesda approves a scientific or behavioral research project, a special committee must review its value, appropriateness and moral/ethical implications. In recent years, Bethesda also has become noted for the development of religious training programs and materials, all of which are tested in Bethesda's classes and then published for use in parish and community settings.

f. "A vector for developing community awareness, understanding, participation and acceptance of persons who are mentally retarded."

Through its publications, movies and videotapes, through its volunteer program, and through tours, Bethesda works daily to break down barriers for retarded persons. Over 5,000 volunteers a year come to Bethesda to assist with camping and recreational activities, perform in programs, share classroom activities or simply serve as friends. All leave with new understanding of the needs and feelings of retarded persons.

g. "Instilling morale that fosters interest and pride in the daily duties of the staff."

"You just can't stop trying," said our Speech Therapy supervisor the other day as she was talking about all the things her department has tried to help one of our residents, who has cerebral palsy and cannot speak. To help him communicate, our speech therapists have tested a variety of communication boards placed at different locations on his wheelchair, a focused light, a bell, a "speller-teller," and a differently-positioned wheelchair. They still have not found the right answer but the "trying" goes on, with the aid of consultants and engineers -- because they want to and because they care.

Staff members also are enthused about involving our residents in the community. The staff take the residents out to dinner, to the community drop-in center, arrange shopping trips and numerous recreational outings, and encourage community schools and organizations to participate in classroom activities. This integration process has created a positive reaction from Watertown, the community in which Bethesda is located.

h. "Creating an overall climate of hope, understanding and determination."

Bethesda is known as "a haven of hope." People who visit comment frequently on the happiness of both the residents and staff. It was because of this unique atmosphere that Bethesda was made the subject of an NBC Television special ten years ago, entitled "No Miracle But Love."

* * *

In all of these ways, the institutional setting is better than group homes for seriously retarded individuals. Placement of such individuals in group homes would be a more restrictive rather than a less restrictive alternative.

4. S. 2053 Would Make It Much More Difficult for Retarded Citizens to Exercise Their Religious Freedom.

Bethesda is associated with the Lutheran Church and provides an opportunity for worship and spiritual growth to its residents. Bethesda's chapel has been especially designed to permit handicapped people to develop a religious life without any physical barriers. At Bethesda residents attend daily chapel services and weekly Bible classes, participate in voice or handbell choirs, belong to the Altar Guild and receive religious counseling by persons trained to meet their needs.

Unfortunately, the opportunity to practice their faith and to grow spiritually is often not available to retarded people in the community. Many congregations simply fail to provide such opportunities and it is difficult to imagine how retarded citizens, especially severely retarded citizens, could enjoy spiritual growth in a non-church affiliated group home. Large institutions, whether church-affiliated or secular, are in a much better position to offer religious services to retarded citizens than are group homes.

5. S. 2053 Assumes, Without Basis, That the Cost of Implementing Group Home Care for Retarded People Would Be Less Than for Institutional Care.

An assumption underlying S. 2053 is that group home care for retarded people would be less expensive than institutional care. Bethesda believes that the cost of implementing S. 2053 should be investigated in depth. Among the factors which should be included in such a cost study are the following:

- -- The expense of building, buying or leasing the more than 10,000 group homes needed to house the 125,000 to 150,000 people now living in large institutions.
- -- The cost of supporting community services such as workshop training, therapies, education, medical care, respite care, domestic assistance and transportation.
- -- The expenses associated with the expanded state inspection teams needed to ensure that the residents in group homes do not suffer from abuse.
- -- The expenses associated with the expanded state or county social service staff which would be required to coordinate and manage the placements into group homes.
- -- The costs of training programs needed for the group home staffs.

Unless careful attention is given to these and other factors, the costs of group home care will be grossly understated.

6. S. 2053 Does Not Take Into Account the Failures, Nor Prevent Repetition of the Abuses, Which Have Resulted From Previous Deinstitutionalization Programs.

While many individuals have been released from institutions in recent years, many have been readmitted to other institutions because sufficient support systems do not exist in the community. Deinstitutionalization has been largely a process of reinstitutionalization -- shuffling retarded residents through devastating experiences in independent living, then placing them back into an institution when the community experiment fails. Community facilities are not inherently normalizing. In fact, they can be as restrictive as the worst possible institution if the setting is inappropriate and the residents are unsupported by the services they require.

The failure of the deinstitutionalization effort for the mentally ill is well known. For example, in Illinois, the process has come full circle (Radmila Manojlovich, "A Scandal in Mental Health Care" (American Federation of State, County and Municipal Employees (Illinois Council)) at page 31):

> "The mentally ill -- by the tens of thousands -- have been discharged from the large public facilities. However, they have not been placed in smaller care facilities that are integrated into real communities. Instead, they have been dumped into other institutions -- nursing homes, boarding homes and the like -- none of which are part of any community. The mentally ill have not been deinstitutionalized. They have been reinstitutionalized."

Great care must be taken to ensure that the problems which have attended the deinstitutionalization of the mentally ill do not repeat themselves in the deinstitutionalization of mentally retarded individuals. However, disturbing signs of the deinstitutionalization/reinstitutionalization cycle have appeared in states like California and Minnesota. The wholesale deinstitutionalization contemplated by S. 2053 puts many retarded citizens at risk of suffering through this deinstitutionalization/reinstitutionalization cycle.

7. S. 2053 Ignores the Human Effects of Deinstitutionalization on Staff Members Who Care for Retarded People, on the Community At Large and on the Families of Retarded Persons.

The deinstitutionalization doctrine championed in S. 2053 also ignores a number of basic human factors. The following factors cannot be ignored if community placement of mentally retarded citizens is ever to be successful.

a. The Staffs of Group Homes Have High Turnover Rates.

The national average for length of service for staff in a group home for mentally retarded individuals is 18 months. If large numbers of new group homes are opened, these staffing problems will only be exacerbated. Where staff members are unhappy and not closely supervised, the potential for fraud, neglect, low quality programming and physical abuse of residents is great.

b. S. 2053 Makes No Provision for Funds to Change Community Attitudes.

Bethesda's biggest struggle in establishing group homes is finding a neighborhood where the neighbors do not object, where zoning is appropriate, and where the retarded residents can truly become part of the community. Placing retarded people where community resentment exists reduces their self-esteem and creates a sense of isolation. S. 2053 does not confront these issues and provides no funding mechanism to aid the process of community integration.

c. Inability of Many Families to Cope With a Retarded Family Member.

Many families experience guilt over being unable to handle the retarded family member in the home. Divorces and problems with "normal" siblings are common in families with a retarded member. Because many retarded people have normal life-spans, families must also struggle with questions such as how to care for the retarded member as the parents grow old and who is to care for the retarded person after the parents' death.

For many families the very essence of the term institution -- the notion of permanency and continuity -- gives them comfort that the retarded individual will be cared for after they have succumbed to the infirmities of old age or death. The specter of a retarded son or daughter being shuttled from facility to facility with no one left to "care" is the ultimate nightmare that haunts parents of retarded children.

8. S. 2053 Is Not a Necessary Prerequisite to the Development of Group Home Care.

One must not lose sight of the fact that group homes may be funded without removing funding from institutions. Indeed, Medicaid funds are available today to community-based Intermediate Care Facilities for the Mentally Retarded (ICF-MR) of 15 beds or less. The reason most states have not chosen this route to funding group homes is two-fold. First, the certification standards are very high (*e.g.*, each home must have a nurse on contract, and residents must be recertified by a doctor every two months). Second, the cost of operating such facilities at the required standard is substantially higher than the Medicaid coverage provided. With this history, the prospect of success for the group home concept which lies at the heart of S. 2053 is extremely limited.

CONCLUSION

No one solution can be best for all retarded people. The wholesale move to deinstitutionalize contained in S. 2053 would severely disserve the best interests of many retarded citizens. Bethesda urges the Subcommittee on Health not to lose sight of this fundamental principle as it continues its review of the best mix of services and federal assistance for retarded citizens. Bethesda thanks the Subcommittee for its willingness to examine all options for providing care to this Nation's retarded population.

TESTIMONY PRESENTED TO SENATE FINANCE COMMITTEE ON COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983, S.2053

ON BEHALF OF

NATIONAL ASSOCIATION OF SUPERINTENDENTS OF PUBLIC
RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED

By Bernard R. Wagner, Ph.D.
Immediate Past President and
Chairman of the Legislative Committee

I am Bernard R. Wagner, Ph.D., Superintendent of the Georgia Retardation Center, Atlanta, Georgia, and am speaking on behalf of the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded. This organization is comprised of approximately 180 chief executive officers of state institutions serving mentally retarded clients. The purpose of this presentation is to express our opposition to the proposal entitled "Community and Family Living Amendments of 1983". As currently written we feel that these amendments could carry the potential of seriously harming services offered the mentally retarded clients whom we serve.

Our first grounds for opposition to this proposal lie in the proposal's rigid adherence to the elimination of Medicaid funding for state institutions except for a total of two years of care. I should point out in this context that our Association consistently for the last ten years has enthusiastically supported the development of appropriate community based alternatives to institutional living. We as an organization, however, feel that emphasis should be placed upon each state developing a full continuum of services and that in many, if not all, states this continuum of services would probably include some limited institutionally based services. For example, there are significant numbers of clients currently in institutions who require relatively sophisticated and intensive services which would be impractical and uneconomical to deliver in a family-size setting in community. Many clients are profoundly retarded with medical surveillance from licensed physicians and nursing personnel, and also require a wide variety of specialized services such as adaptive equipment, physical therapy, and occupational therapy. Other clients require intensive behavior modification programs because of severe behavior problems. In this context many states are now beginning to realize that they are not adequately serving two very difficult populations - mentally retarded offenders who all too often are placed in correctional facilities, and duel diagnosis clients with both mental retardation and psychiatric problems who are inappropriately placed in psychiatric settings.

Most states in planning for their continuum of services will probably come to the conclusion that such highly sophisticated services are most humanely and cost effectively delivered in an institutional rather than community setting. The problem with the amendments as proposed is that the states would not be allowed this option under Medicaid funding.

A second problem which we have with the amendments as proposed is that they appear to us to be based on incomplete and inconclusive data. While studies quoting that community based services are more economical than institutional based services are probably accurate when speaking of the mild and moderately retarded clients without major behavior problems, there is an insufficient data base to draw similar conclusions regarding cost effectiveness when one considers the types of populations requiring intensive services described in the preceding paragraph. Furthermore, we feel that the amendments are based on somewhat untested philosophical rather than data based positions. For example, an assumption is made that by simply placing retarded clients in community in smaller residences the eventual result will be a less restrictive, more normalizing environment. Informed professionals in the field are beginning to recognize that this is a gross oversimplification, and that in many cases programs and services exist in institutions which are in fact more normalizing and less restrictive than a number of community based programs which meet the criteria of size and location. Unfortunately, the field of residential services for the mentally retarded has been a field all too frequently dominated by philosophical based rather than data based positions. We certainly feel, as leaders in the field of residential services for the mentally retarded, that our decisions as to what the future of each state's system should look like should be based on data as well as philosophy, and that hard data regarding the delivery of services to those residents currently in state institutions requiring intensive levels of care has certainly not yet been developed.

The absence of complete data regarding the reported efficiency of community over institutional placement can be highlighted on two grounds. First, many of the studies in this area compare the cost of serving mild and moderate clients in community with the cost of serving severe and profoundly involved clients in institutions. Second, some of the apparent savings in the community result from common community practices of paying minimal wages to staff, whereas state institutions use a much higher salary structure. If emphasis is placed on moving institutional staff out into community as we depopulate institutions, and such staff retain their salaries and benefits, much of the apparent cost effectiveness of community settings will be significantly reduced.

A third basis for our opposition to the amendments as proposed is that we feel that the mechanism for encouraging the growth of community based services already exists in the Medicaid Waiver Program. We as a group do support the planned movement of retarded residents out of institutions into the community and the shifting of the emphasis away from institutional services towards community base services. Most states, 37 at this point, have already had Medicaid waiver plans approved, and it is our understanding the remainder of the states are in process of developing their necessary deinstitutionalization plans. It would appear to us that the Medicaid Waiver Program provides sufficient incentives to states to make the appropriate shift in the service system from institution based to community based, while still allowing each state the flexibility to develop a system of service involving a comprehensive continuum of services offering the variety of services and settings our retarded citizens deserve.

In summary, it is our desire through this presentation to express our serious reservations regarding the proposed "Community and Family Living Amendments of 1983". We feel that these amendments are too restrictive in that they eliminate entirely the possibility of a state planning to provide some of its services in institutional settings, that the amendments are based on philosophical positions rather than data based, and that we are very concerned that the clients whom we currently serve in our state institutions might have to settle for less intense, less sophisticated, and perhaps inappropriate services based in community if these amendments are approved and promulgated as currently written. We are as an organization totally committed to the development of quality services, but would put the emphasis on each state developing its own well-thoughout continuum of services rather than a federal dictation that these services may not include any institutional based services. We stand ready to provide additional information through testimony, surveys of our facilities, or any other device you might deem appropriate as you consider the very complex and significant issues involved in this area. I am sure we share a common goal of attempting to develop the most appropriate, cost effective services for mentally retarded individuals which uses our scarce federal Medicaid resources in the most appropriate and cost effective manner.

CONGRESS OF ADVOCATES FOR THE RETARDED INC.

TO ADVANCE
"...the interests of mentally retarded persons in achieving appropriate education, housing, medical and other services"

446 BERNARDSTON ROAD • GREENFIELD, MA 01301 • (413) 773-5155

SENATE BILL 2053
OPPOSED BY
CONGRESS OF ADVOCATES FOR THE RETARDED, INC.

PRESENTER: BARBARA KONOPKA, PRESIDENT
DATE: FEBRUARY 20, 1984

SUMMARY

DEINSTITUTIONALIZATION (AFFECTING MENTALLY RETARDED PERSONS):

CAUSE OF DEATH, DESTRUCTION AND DEGRADATION OF HUMAN LIFE.

LEAST RESTRICTIVE SETTING:

NOT ALWAYS THE COMMUNITY.

FAMILY INVOLVEMENT:

THE MOST IMPORTANT ENTITY IN PLANNING SERVICES.

FACILITIES AS COMMUNITIES:

MODELS EXIST -- A MATTER OF WILL.

TRUTH IN ADVOCACY:

NEED FOR BOTH COMMUNITY AND INSTITUTIONAL PROGRAMS.

RESTRUCTURING OF MENTAL HEALTH SYSTEMS:

MAKING RESOURCES (TAX DOLLARS) BENEFIT MENTALLY RETARDED PERSONS.

TO: U. S. SENATE FINANCE SUB-COMMITTEE ON HEALTH
RE: COMMUNITY AND FAMILY LIVING AMENDMENTS ACT OF 1983 (S. 2053)

FROM: BARBARA KONOPKA, PRESIDENT (Mrs) Barbara Konopka
CONGRESS OF ADVOCATES FOR THE RETARDED, INC.

DATE: FEBRUARY 20, 1984

"THE PARENTS' VOICE"

During the past two decades, the mass-movement to deinstitutionalize mentally ill patients from hospitals and mentally retarded persons from residential centers included misuse of court systems to accomplish idealistic, libertarian goals in the name of "residents' rights to treatment in least restrictive environments". By the late 1970's, parents and relatives of retarded persons living in public residential care and treatment facilities found the reasonableness in their lives turned upside down by the movement to do away with a choice in care for developmentally impaired individuals.

Congress of Advocates for the Retarded, Inc. was organized in 1979 when a small but determined group of parents stood up and said "NO -- FOR MANY OF OUR CHILDREN, PUBLIC RESIDENTIAL CENTERS ARE THE 'LEAST RESTRICTIVE ENVIRONMENTS'". The priority goal of CAR is to keep these residential centers for care, training and treatment of severely and profoundly retarded persons an alternative for families who bear the burden of dealing with this developmental disability.

THESE FACILITIES MUST BE UPGRADED AND TRANSFORMED INTO SPECIAL COMMUNITIES FOR RETARDED PERSONS WHO REQUIRE SAFE ENVIRONMENTS.

The numbers are many and voices strong among those who speak with disregard of the true needs of the severely and profoundly handicapped in our society.

Under the United States Constitution, this segment of our retarded population is entitled to adequate and appropriate care. This is the basic, realistic intention of our organization, to see that this group of individuals who need special love and special attention are not sacrificed and lost in the process of bettering the lives of retarded persons in general. We are avowed in advocacy for all retarded persons without exclusion of any who have extraordinary needs.

Since the early days of incorporation, CAR has received tear-stained letters from parents and relatives of retarded persons, distraught from the insensitive attitudes of social scientists who develop plans that thrust their loved ones into situations where they cannot cope. We have communicated with Federal and State Legislators, our membership and the general public regarding the many tragedies that have befallen retarded individuals who have been cast onto the streets of an uncaring society. Yet, the process continues with a seeming disregard for the very serious, sometimes fatal consequences. Many state mental health systems pledge allegiance to the philosophy of "normalization" to the extent that the retarded persons needing services simply become so many apples and oranges. Until these swollen bureaucracies are broken down, the most seriously mentally handicapped in our society will continue to received only a small fraction of the resources allocated for their care and treatment. IN AMERICA TODAY, WE CAN DO THE JOB OF PROPERLY SERVING OUR RETARDED POPULATION. THE RESOURCES ARE THERE. TO DO IT EFFECTIVELY AND WELL, THERE MUST BE BOTH COMMUNITY AND INSTITUTIONAL PROGRAMS.

On November 4, 1983, Senator John Chafee of Rhode Island introduced as S.2053, COMMUNITY AND FAMILY LIVING AMENDMENTS ACT OF 1983. This bill, as written, would accomplish basicly what the ARC US bill intended to do, eliminate a necessary part of service delivery to retarded persons, the total-care residential center.

Congress of Advocates for the Retarded strongly opposes S.2053 and concludes this written testimony with the following text taken from a letter now being distributed nationally to make known our position,

"We do not believe that one type of care should exist at the expense of the other, nor that only one type service is best for all mentally retarded individuals. For many mentally retarded citizens the institutional setting with its many support services is best. For other lesser handicapped mentally retarded citizens the group home, supervised apartment or some other alternative service may be appropriate. We believe in a continuum of quality care, not just one type of care.

A majority of our members have a family member in a public institution. Most of our members have expressed concern over Senate Bill 2053. After reviewing the proposed bill we find that it would be detrimental to mentally retarded individuals who need institutional care. Institutions have in many states served as the innovators and leaders in quality care for the mentally retarded. Many of the nations better community programs are supported totally or in part by institutions. To curb funding to institutions would not only hurt institutional services, but would also hurt community services.

Many other reasons including impact on the mentally retarded individual's family; zoning law changes (we do not want mental retardation ghettos); the negative effect of this proposed law in rural states with limited health care and mental retardation professionals; the unproven cost of the type of care being proposed; and the unproven quality of care to be rendered (the professional reviews and variety of professionals in an institution can not be duplicated in a small group home at less expense and thus care in the group home may not equal the quality of the care in institutions); have led us to oppose Senate Bill 2053."

Testimony on Community and Family Living Amendments of 1983,
S.2053 by
Pasquale Accardo, M.D.

The nauseating stench of institutional settings for the handicapped has permanently scarred the olfactory sensibility of parents and professionals involved with the retarded for many decades. This abomination is thankfully decreasing in frequency and becoming a terrifying memory rather than a reality - there are fewer institutions, institutions are smaller, there are less inmates in institutions and the standards of quality for the surviving institutions are (underfire) continually improving.

The movement away from institutional settings and towards community placements as part of a general program of normalization is both laudable and deserving public and professional support. It is not inappropriate that part of this support be legislative and financial. The history of the institutional movement in the United States is one of almost unrelieved horror, professional incompetence and public apathy. Starting with the best of intentions, that movement quickly degenerated into an inhuman warehousing of human beings that distorted and then justified the mistaken observations and opinions of psychologists, geneticists, physicians, educators, administrators and bureaucrats. For too many years, severely retarded persons, mildly retarded persons, nonretarded persons, and emotionally disturbed persons were indiscriminately and irrationally segregated from the community in settings that had started out with the goal of education for return to the community but quickly declined in enthusiasm and rapidly evolved into a hell on earth, a concentration camp for nonpersons without papers. These errors, abuses, and self-delusions were thoughtlessly propagated and informed later lay and professional opinion about the handicapped. It has long been clear that an alternate approach was dictated by advances in (as well as a truer prespective of past achivements in) medicine, education, psychology, philosophy, theology and humanity.

That the old pattern of institutionalization needs to be erradicated root and branch goes without saying. But the greatest error inherent in that approach was to consider all retarded persons to be the same - to have the same minimal needs that could best be met by a segregated warehousing. Retarded persons are not all the same: they exhibit as much, if not more, variation than the nonhandicapped population. To presume that all severely retarded persons can function in group home settings makes about as much sense as assuming that all nonretarded persons can function best in a home setting. Some retarded and some nonretarded persons have special needs that can only be met in more specialized settings. The optimal placement for a person with one specific medical diagnosis (albeit an exceedingly rare one), hydranencephaly, is an intermediate care facility with readily available medical support services. This is also the ideal type of placement for persons with either similarly severe organic brain syndromes, other severe medical conditions, or similar functional levels. The need for this type of placement is permanent and not short term. It is necessary for a small but important segment of a special needs population. That the majority of severely retarded persons may do well in group home settings is no excuse to ignore the needs of this minority. That group homes need legislative and financial support is no rationale for withdrawing such support from those with different and greater needs. The population in need of intermediate care facility placement is more limited, more dependent and most defenseless. It verges on criminal irresponsiblity to make the growth of one phase of the service delivery system dependent on the erradication of an equally necessary phase. That resources need to be shifted - that many clients currently in institutional settings would do better in group homes can surely be implemented without blindly removing all funding support from more specialized intermediate care facilities.

Perhaps the impact of this legislation might be clarified by a rough analogy to a similar dilemma in the care of the elderly. Aged grandparents may stay at home with their family, and may live in community based retirement villages or they may be segregated in nursing home facilities. Part of the decision as to life style is a matter of personal choice, but medical and physical limitations may sometimes make certain of these options impractical and unrealistic. The family with a severely limited grandparent (scil. severely retarded grandchild) is being told that unless they are willing to let their grandparent live in a group home setting, their only other choice would be to keep them at home. Permanent/long term nursing home placement is no longer supported. Indeed, if they pay for that nursing home placement out of their own pocket, medical services that would otherwise have been covered will not be. Now even the best nursing homes for the elderly, should never be our first choice, but they do remain a necessary form of care in certain selected cases. Continued financial support for this third option provides the best possible entrance for regulating the improvement of standards and quality of care in such settings.

It is necessary to confess that the medical profession has little interest or expertise in the provision of quality care to the severely retarded population. An informal attempt to survey the meeting of the most basic medical needs of this special population in community based settings routinely produces blank stares. It is not so much that the answers are inadequate; the questions have not yet been framed. It is only in the past 20 years that pediatrics has reluctantly and slowly moved towards admitting gross ignorance in the medical management of the developmentally disabled. A full correction of that almost criminal ineptitude will take at least the remainder of the present millenium. The numerous problems inherent in the provision of routine health maintenance for the severely retarded in community based group homes has been glibly ignored on the facile assumption that if they qualify for such a placement they can probably be treated just like anyone else at the nearest clinic, doctor's office or other health facility. If professionals and families would trouble their brains ever so briefly to recall the nightmare of medical ignorance, incompetence, and callous neglect that retarded adults were victimized by as children, they might not feel so complacent about presuming the availability of routine health services. Indeed, they ought to be absolutely terrified about future possibilities for the simple reason that there has been relatively little change in the attitudes and opinions of the medical profession towards the severely retarded over the past century. For every physician who has been converted to accept the mildly retarded person and the Down Syndrome adult into the community, there is another (if not the same) physician who would strongly support the refusal of extraordinary care (e.g., feeding) if not actually euthanasia for the severely and profoundly retarded and handicapped. This legislation testifies to an abysmal ignorance of the state of preparedness (psychological, ethical, organizational and educational) of the medical profession to even passively be drawn into its implementation. For families with profoundly impaired members with specialized medical and paramedical needs, this legislation must appear to have been drafted in cloud cuckoo land.

The population of the United States is approximately 230 million. The prevalence of mental retardation is approximately 3%. Of the almost 7 million retarded persons in the United States, about 6 million are only mildly retarded; these persons should have benefited from special education services so that they are (or will be) functionally literate and capable of independent living with minimal social support services. In an accepting environment, such persons should not need segregation in a stigmatized facility such as a community based group home setting. There are about 1 million Americans who are moderately retarded: these persons can be trained to useful employment and can do quite well in group home settings. It must, nevertheless, be remembered that some moderately retarded persons with good social skills may do well in a less restricted environment, while some few others may have long term problems in coping with a group home setting. As the cognitive limitation becomes more severe, the incidence of associated medical and physical problems also tends to increase. Rising mortality and morbidity and shortened life span are correlates of severe and profound mental retardation; they are hallmarks of the increased special needs of this subpopulation which represents only a small proportion of the total mentally retarded population - with less than a half million severely and less than a hundred thousand profoundly retarded persons in the whole United States. Persons in the profoundly retarded range have intelligence quotients below 25, mental ages below 4 years of age, frequently have no useful speech and often have severe physical problems and disabilities such that independent mobility is significantly limited. While many persons in the severe range of mental retardation can function in group home facilities, some can not; conversely, most profoundly retarded individuals will not be able to function in group home facilities, while some few will. Any legislative change needs to support the widest possible range of choices for living conditions, a range that needs to be carefully titrated against a complex array of individual needs. Failure to allow for the complexity of the human needs involved can become a self-fulfilling prophecy: an increased mortality rate for a segment of the severe and profoundly retarded and handicapped population inappropriately placed in group home facilities will be a mute testimony to the ideological poverty that informs the proposed legislation. Thy hydranencephalic patients mentioned above are traditionally accorded a lifespan of less than 1 or 2 years by medical specialists; superior intermediate care facilities are demonstrating that that limitation is artificial. The group home placements that are contemplated would most probably reinstate the validity of the gloomier medical prognosis.

The ability of human beings to function optimally is enhanced by increasing the options at their disposal. This legislation reduces options and does so drastically, with such a lack of foresight as to appear malicious. It used to be feared by parents and professionals that the use of alternate modes of communication, such as sign language and electronic communication devices, would cancel any progress towards the acquisition of speech. Experience has taught us that alternate modes of communication not only enhance the overall quality of life for disabled persons but actually tend to increase the development of spoken language. Quality long-term and intermediate care facilities are needed choices on the spectrum of possible living arrangements for severely and profoundly retarded and handicapped persons. The judicious use of such settings will enhance the quality of life in selected cases and will also contribute to maximizing the impact of group homes on the quality of life of their residents.

The teeth in this legislation bite in only one direction: funding for existing intermediate care facility programs - even those doing an excellent as well as necessary job - will be cut (there is no leeway in that decision) - and patients will be hurt thereby. On the other hand, while some of these cut funds will be transferred to group home facilities, there are no teeth to insure that these latter facilities will be funded sufficiently to even begin to supply the same services on a decentralized basis. Indeed, the government's track record indicates (if it does not actually guarantee) critical funding deficits in this area. The teeth in this legislation bite only the flesh of the severely and profoundly handicapped and retarded.

This bill is, in a way, attempting to tell the entire United States of America that a New England town meeting is the only acceptable form of local government. The success of that model in the locale where it evolved is striking. Its proposed transplantation by legislative fiat to be imposed on the broad diversity of communities in the 50 United States each with their own regional history and local practices, some in need of improvement but many excellent, is a political nightmare.

The great American philosopher, George Santayana, warned that those who did not learn the lessons of history would be forced to repeat them. Of all the errors of the past, the pattern most terrifying to repeat is that of the swinging pendulum. The replacement of one extreme by its opposite, the correction of one erroneous course of action by the opposite evil, smacks so much of the mechanical, of a Hegelian or Marxist dialectic, that it must appear abhorrent to free men. Bruckberger in his Image of America noted that it was the glory of America, the virtue of the American political system, the key to the success of the first of the world's great revolutions, that it avoided trying to legislate utopian ideals but instead remained rooted in practical compromises. S.2053 is uncompromising, unamerican, inhuman in its extremism and, if passed, will be judged by history as the action of men and women too blinded by narrow ideology to take any notice of the human suffering that could have been avoided.

Statement on The Community and Family Living Amendments (S2053)

Submitted by

The American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP)

NOTE: Acknowledging the high level of current discussion and concern regarding the issues involved in S 2053, the Board of Directors and staff of the AAUAP used the occasion of their mid-winter Board meeting to formulate the following statement. Subsequent to its distribution to the AAUAP Membership for input and refinement it was formally submitted as testimony for the record on Friday, March 16, 1984.

I. Background Factors

- It was agreed that there has been a documented historic failure of state residential facilities ("institutions") to respect the dignity of individuals and hence they have suppressed human potential and value.
- It was further noted that irrespective of the level of financial assistance, centralization of services in institutions does not insure provision of appropriate therapeutic and support programs.
- Deinstitutionalization experiences in Pennsylvania, Michigan, and New York, for example, have shown that the quality of life has improved after discharge (at a cost which has been somewhat less) as judged by the views of clients, families, and service providers.
- We have now learned that there are no individuals who cannot be effectively served in the setting of community residence.
- Community-based programs appear to provide many personal benefits which have as yet not been clearly and systematically demonstrated, but which show important promise.

II. Reflections on Current Realities

- Current Title XIX reimbursement regulations provide a suppresive atmosphere for the development of community alternatives, which could seriously delay or prevent new and vital program improvement.
- There is a need to modify the existing motivations leading to the placement of handicapped individuals in more supportive and creative environments.
- Preparation for community life, or assurance about the feasibility of this plan, cannot be carried out successfully within the institutional setting alone.

- o It is not clear whether or not attitudinal factors in the social scene must be entirely revised before progress can be made in achieving gains for exceptional individuals.

- o There are many gratifying elements in the S 2053 language about specific measures - individualized plans, safety, residential settings, etc.

III. Cautions about the Planned Steps

- o Most landmark legislation in behalf of handicapped persons has been based on rights and incentives. However, a major component of S 2053 is based upon a disincentive model of legislation.

- o Inasmuch as the proposed legislation will have the effect of pressing for the final return of all institutionalized persons to the community, this must be preceded by systematic planning for and a concomitant commitment regarding community-based support.

- o Training in the developmental model is needed for (a) the gatekeepers, (b) the primary care workers, and (c) the providers of related services.

- o The suggested legislation may not go far enough in consideration of the range of broad supports needed for families in order to maintain their handicapped children at home or alternative community placements.

IV. Conclusion

The AAUAP feels that the Community and Family Living Amendments of 1983 are so important and valuable that we vigorously endorse the intent and philosophy of this legislation.

AMERICAN FOUNDATION FOR THE BLIND, INC.

GOVERNMENTAL RELATIONS DEPARTMENT

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STATEMENT OF

THE AMERICAN FOUNDATION FOR THE BLIND

BY

GLENN M. PLUNKETT
SPECIALIST IN GOVERNMENTAL RELATIONS

TO THE

SUBCOMMITTEE ON HEALTH
COMMITTEE ON FINANCE
UNITED STATES SENATE

ON

S. 2053, THE COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983

FEBRUARY 27, 1984

THE AMERICAN FOUNDATION FOR THE BLIND JOINS WITH OTHER ORGANIZATIONS, GROUPS AND INDIVIDUALS CONCERNED WITH THE USE OF MEDICAID FUNDING TO IMPROVE THE CARE AND ASSISTANCE PROVIDED THE SEVERELY DISABLED. WE SUPPORT THE CONCEPT OF S. 2053, THE COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983. HOWEVER, S. 2053 HAS A NUMBER OF FLAWS THAT MAKE IT DISCRIMINATORY AS TO WHOM IT WOULD SERVE AND

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Helen Keller inspired millions throughout the world by her triumph over deafness and blindness. She used her personal miracle of communication to open the world for other blind and deaf-blind people. She appeared before legislatures, gave lectures, wrote articles, and above all, made herself an example of what a severely handicapped person can accomplish. When the American Foundation for the Blind was established in 1921, she found in it a national organization that shared her purpose. From 1924 until her death in 1968, Miss Keller was a member of the Foundation staff, serving as counselor on national and international relations. It was also in 1924 that she began her campaign to build an endowment fund for the Foundation. Through this fund and the kindness of present benefactors her work is continued.

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HOW WELL IT WOULD ACCOMPLISH THE GOAL OF BETTER SERVING THE DISABLED. WE HAVE OUTLINED THOSE POINTS IN THE NUMBERED ITEMS BELOW.

THE AMERICAN FOUNDATION FOR THE BLIND IS A NATIONAL, NON-PROFIT ORGANIZATION WHICH PROVIDES BOTH DIRECT AND TECHNICAL ASSISTANCE SERVICES TO BLIND AND VISUALLY IMPAIRED PERSONS AND THEIR FAMILIES, PROFESSIONALS IN SPECIALIZED AGENCIES FOR THE BLIND, COMMUNITY AGENCIES, ORGANIZATIONS, SCHOOLS, AND CORPORATIONS. DIRECT SERVICES INCLUDE INFORMATION AND REFERRAL FOR BLIND PERSONS, THEIR FAMILIES AND PROFESSIONALS; SPECIAL CONSUMER PRODUCTS; A TRAVEL IDENTIFICATION SERVICE; AND GENERAL EDUCATIONAL MATERIALS. TECHNICAL ASSISTANCE SERVICES INCLUDE TRAINING, CONSULTATION, PROFESSIONAL PUBLICATIONS, PUBLIC INFORMATION, AND SOCIAL AND TECHNOLOGICAL RESEARCH.

WE SUGGEST MODIFICATION TO S. 2053 IN THE FOLLOWING AREAS:

1. THE RESTRICTIONS IN PROPOSED SEC. 1918 ON THE TIME SPENT IN AN INSTITUTION WOULD REQUIRE THE MOVEMENT OF MOST OF THE CURRENT POPULATION OUT OF INSTITUTIONS WITHOUT RECOURSE TO FURTHER TREATMENTS IN AN INSTITUTION, IF NECESSARY. THAT AMENDMENT SHOULD BE AMENDED TO REMOVE THE ABSOLUTE TIME RESTRICTION AND REQUIRE CERTIFICATION OF NEED FOR SUCH INSTITUTIONALIZATION AND RECERTIFICATION AT SPECIFIED TIMES SIMILAR TO MEDICARE CERTIFICATION OF MEDICAL NEEDS FOR PART A OF TITLE XVIII. THIS CERTIFICATION COULD BE CARRIED OUT BY AN "...INTERDISCIPLINARY TEAM OF INDIVIDUALS..." AS OUTLINED IN SECTION 1918(h)(2)(D)(i) FOR THE COMMUNITY AND FAMILY LIVING FACILITY. A SPECIFIC PERIOD OF TIME IGNORES THE

POSSIBILITY OF A NEED AFTER THE STIPULATED PERIOD AND OFFERS NO ALTERNATIVES.

2. THE DEFINITION OF SEVERELY DISABLED RESTRICTS THE BENEFITS OF THE PROGRAM TO CERTAIN TYPES OF DISABLED, AND WOULD TERMINATE THE SERVICES TO THE MENTALLY DISABLED AT AGE 21 EVEN THOUGH HAVING RECEIVED SERVICES UNTIL THAT TIME. FURTHER, IT ESTABLISHES A CUTOFF DATE FOR MANIFESTATION OF "COVERED" DISABILITIES AT AGE 50. MORE THAN HALF OF ALL BLINDNESS IN THE U.S., FOR INSTANCE, OCCURS IN THOSE OVER AGE 50 AND MOST SEVERELY VISUALLY IMPAIRED PERSONS ARE MULTIPLY-IMPAIRED.

   THE DEFINITION OF THE DISABLED WHO WOULD RECEIVE SERVICES UNDER THE PROPOSAL SHOULD BE THE SAME AS THAT FOR DISABILITY/BLINDNESS IN TITLE XVI OF THE SOCIAL SECURITY ACT AND WITHOUT A CUTOFF DATE FOR MANIFESTATION OF THE DISABILITY. THERE SHOULD BE NO AGE LIMITATION SINCE THOSE OVER AGE 50 CAN BENEFIT FROM "LESS RESTRICTIVE SETTINGS" AND HABILITATION SERVICES AS WELL AS THOSE UNDER THAT AGE.

3. THE PROPOSED LEGISLATION SHOULD MANDATE MEDICAID COVERAGE FOR ANY AND ALL INDIVIDUALS WHO MEET TITLE XVI COVERAGE IN ALL STATES. WITH THE CURRENT MORE RESTRICTIVE (THAN SSI) CRITERIA IN SOME STATES, SOME OF THE DISABLED WOULD NOT BE ELIGIBLE FOR ALL SERVICES.

4. THE PROPOSED LEGISLATION SHOULD GIVE MORE FLEXIBILITY FOR THE STATES IN THE PHASE-OUT OF MEDICAID FUNDING. THERE ARE NOT SUFFICIENT DATA TO SHOW THAT THE

PROGRAM CAN BE ACCOMPLISHED WITHIN THE PROPOSED TIMELINES. SOME STATES MAY BE ABLE TO ACCOMPLISH THE PROGRAM AT A FASTER RATE THAN OTHERS. HOWEVER, THE LEGISLATION SHOULD REQUIRE STATES TO MAINTAIN THE NECESSARY LEVEL OF SERVICES DURING THE PHASE-OUT.

5. SOME CONSIDERATION SHOULD BE GIVEN TO ASSISTANCE IN FUNDING THE PURCHASE/RENTAL OF A COMMUNITY FACILITY, AND IN TRAINING FOR MANAGEMENT THEREOF.
6. RECOGNIZING THAT NATURAL/ADOPTIVE FAMILY STRUCTURES WILL BREAKDOWN OVER THE YEARS EITHER THROUGH AGE, DEATH, SEPARATION, OR ILLNESS, THE ACT SHOULD ENSURE THAT AN INDIVIDUAL PLACED IN SUCH AN ARRANGEMENT HAS SUBSEQUENT CARE.

WE HOPE THAT THIS EFFORT TO PROVIDE ALTERNATIVES TO INSTITUTIONALIZATION WILL BE SUCCESSFUL.

* * *

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Statement of

The American Federation of State, County
and Municipal Employees, AFL-CIO

on

S.2053, The Community and Family Living
Amendments Act of 1983

for the

Subcommittee on Health
Senate Committee on Finance

March 16, 1984

in the public service

The American Federation of State, County and Municipal Employees (AFSCME) represents more than one million public employees throughout the United States, including 100,000 who provide direct care and support services to individuals with developmental disabilities. AFSCME members work in large developmental centers as well as in small community residences and apartments, group homes, and day programs. They work as therapy aides and social workers, housekeepers and speech pathologists, secretaries, dietary personnel, firefighters, nurses, maintenance staff, case managers, and physical therapists. On a daily basis, AFSCME members work to promote the health, safety, growth, and development of severely disabled people. Our commitment to promoting the interests of the developmentally disabled through a service system characterized by individualization, accessibility, and a full continuum of care requires that we oppose S.2053, the Community and Family Living Amendments Act of 1983.

This legislation would phase out entirely Medicaid funding over the next ten to fifteen years for mental retardation facilities that house more than three times the number of individuals in an average family household. States would be required to file written plans and timetables for reducing their institutional population to zero. During this phase-out period, severely disabled individuals would still be entitled to Medicaid coverage for institutional services only when no community or family arrangements are available, and provided that the total time such an individual has resided in an institution does not exceed two years. States would have the options to continue to operate institutional programs, but would have to do so entirely with state funds. Following the phase-out period no developmentally disabled person, irrespective of severity of impairment or the wishes of his or her parents or guardians, would be eligible for Medicaid coverage in an institutional setting.

If our experience has taught us anything, it is that the starting point for any system of services for individuals with developmental disabilities must be the individual disabled person. Implicit must be the recognition that, like medications, programs, services, and settings cannot be prescribed uniformly on a class basis, but must be determined according to the specific needs and condition of each disabled beneficiary. Individualization recognizes not only that the needs of each person differ, but also that each client's requirements for services may change many times during the course of a lifetime. S.2053, however, would subordinate the concept of individualized care to the programmatic requirements of a very narrow and absolutist treatment ideology. If enacted, S.2053 would seriously disrupt the continuum of services necessary for individualized care, and in the process jeopardize the security and well-being of tens of thousands of this nation's most vulnerable citizens.

Of the approximately 128,000 persons residing in public residential facilities for the mentally retarded and developmentally disabled, 80% have I.Q.'s below 35 and a maximum mental age of less than 4 years. Sixty percent have one additional major handicap; 37% have two or more handicaps in addition to mental retardation. Fifty-five percent are unable to dress themselves. Fifty percent are unable to speak. Forty-nine percent are not toilet trained. Thrity-five percent cannot eat without assistance. Twenty-five percent exhibit severe behavioral disorders that create danger for themselves and others.1/

While upwards of 96% of this nation's people with developmental disabilities aready live either at home or in other community placements, those who remain in public residential facilities require specalized medical and other services merely to survive.2/ They require intensive individualized care and programming from a variety of specialties and disciplines if only, in many cases, to prevent a deterioration in their current levels of functioning. State developmental centers are more than bricks and mortar. Advances in medicine and the behavioral sciences, judicial intervention, and Medicaid's ICF-MR program have transformed state institutions from predominantly custodial facilities to multi-disciplinary, client-focused developmental centers which - at their best - reflect and extend state-of-the-art programs and services in the care and treatment of profoundly retarded, multi-handicapped individuals.

Medicaid's role in this transformation, and in the promotion of the health and welfare of this extremely vulnerable population, cannot be over-emphasized. The Intermediate Care Facility for the Mentally Retarded (ICF-MR) regulations which were first published in 1974 (as 45 CFR §§249.12 and 249.13; now 42 CFR 442, Subpart G), provide the only assurances on a national basis that developmentally disabled people will receive adequate individualized services and humane care. As a condition for Federal funding - which ranges from 50% to 77% - facilities under this program must provide individualized planned services for each client, comply with normalized living and privacy standards, and provide sufficient numbers of appropriate and adequately trained staff. In addition, facilities must meet strict architectural standards for life safety, fire protection, sanitation, privacy, and home-like surroundings. Between 1977 and 1980, 39 states appropriated or spent nearly $1 billion in capital expenditures for mental retardation facilities - 75% of these outlays were devoted to projects directed toward bringing state facilities into ICF-MR compliance. 3/ All such expenditures, it should be noted, were made with the understanding that long term financial obligations in connection with these necessary capital improvements would be amortized, in great part, with Medicaid dollars.

To withdraw Medicaid support from state institutions would be to undermine those advances that have significantly improved the quality of life for tens of thousands of severely and multiply-disabled individuals. States that had counted on Medicaid reimbursement to amortize construction and operating costs could be expected to slash institutional programs, reduce staffing levels, and severely restrict maintenance and capital improvement. Rather than risk the expenses and vicissitudes of uncertain federal program and funding policies, states would be encouraged simply to abdicate all direct care responsibilities. The effect of a forced dismantling of public institutions would be the dismantling as well of the public provision of services and care. Simply put, it is easier to provide paper "assurances" than actual services, and many states could be expected to take the route with the least potential for administrative or political risk.

By discouraging the public sector's role in the direct delivery of services to the developmentally disabled, S.2053 would promote the proliferation of a "non-system" of programatically and administratively unrelated provider entities of widely varying quality, competency and commitment.[4] Pressures on state and local officials to recruit and maintain sufficient numbers of independent community vendors would be at odds with the tough regulatory role these same officials would be required to assume in order to enforce strict quality standards. The result would be a provider-driven arrangement of therapeutically and administratively unrelated programs lacking comprehensive planning, guaranteed continuity of care, accountibility, universal access, program diversity and balance, and consistently applied standards of quality.

It must be emphasized that while the changes envisioned under S.2053 are drastic and disruptive to the lives of thousands of severely disabled people, the premises underlying this bill center on ideology rather than empirical observations. While anecdotal comparisons abound, there is no professional or empirical consensus to support the presumptions that:

- Facility size is the most significant determinant for positive client outcomes, especially for profoundly retarded and multiply-disabled clients. [5]
- Setting ("community" v. campus) is a primary determinant in positive developmental outcomes for profoundly retarded and multiply-disabled individuals.
- The total cost of serving profoundly retarded and multiply-disabled individuals - holding quality, array, and accessibility. [6]

Proponents of S.2053 cite the experience of Rhode Island and the phase-down of the Ladd Center to support the objectives of this legislation. AFSCME is proud to have taken part in the planning, establishment, and operation of Rhode Island's state-operated system of community, group home, and institutional services. Rhode Island AFSCME members, working closely with state officials and parents, succeeded in upgrading the entire system of care for the developmentally disabled in Rhode Island. It must be noted, however, that the transfer of resources from a predominantly institutional service system to one that is characterized by a full continuum of care occurred with no changes in current Federal law. Similar initiatives have occurred in New York, Massachusetts, and other states without the drastic changes proposed under S.2053.[7] In addition, PL 97-35 (Section 2176) amended Title XIX in 1981 to permit states to obtain Medicaid waivers for the provision of non-institutional, community-based services. Any state wishing to replace its institutional services with alternative services can do so now, under existing law without the draconian measures required under S.2053.

The Medicaid program must not be altered to limit the options and opportunities available for the care and treatment of severly disabled individuals. AFSCME opposes S.2053 because this legislation, if enacted, would deprive medically fragile and vulnerable people of the highly specialized services they require. AFSCME agrees with the preponderance of professional opinion that a balanced, accountable service system characterized by a full continuum of care will best meet the needs of developmentally disabled individuals. This continuum must include high quality institutional and community-based services which meet the individualized medical, habilitative, educational, training and protective needs of developmentally disabled people. Efforts to de-fund any element of this continuum of care must be strongly resisted.

NOTES

1. R. C. Scheerenberger. Public Residential Facilities for the Mentally Retarded, National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, 1982.

2. Inspector General's Report, Department of Health and Human Services, October, 1981.

3. R. Gettings and D. Mitchell. Trends in Capital Expenditures for Mental Retardation Facilities: A State-by-State Survey. National Association of State Mental Retardation Program Directors, Inc., June,1980.

4. Neglect and abuse of the aged and the mentally ill in predominantly privately operated community residences has been widely reported, most recently in Community Residential Care in California, Commission on California State Government Organization and Economy, December 1983. See also: U.S. General Accounting Office, Report to the Congress: Returning the Mentally Disabled to the Community: Government Needs to Do More, 1977; Reports on Hearings by the House Select Committee on Aging: "The National Crises in Adult Care Homes", June 1977; and "The National Crises in Adult Boarding Homes", February, 1978.

5. Heather S. Menninger. Issues in the Development, Programming, and Administration of Community Residential Facilities for Developmentally Disabled Persons: A Review. HCFA, October, 1980

6. See T. Mayeda and F. Wai, The Cost of Long-term Developmental Disability Care, DHEW, 1976; Jones and Jones, The Measurement of Community Placement Services and Its Associated Costs, Florence Heller School of Social Work, 1976; J. G. Murphy and D. E. Datel, "A Cost-Benefit Analysis of Community Versus Institutional Living", Hospital and Community Psychiatry, March, 1976.

Also, recent cost estimates submitted by states seeking Home and Community-Based Waivers under Medicaid show widely varying and inconsistent costs for non-institutional services. One approved waiver, targeted to serve 300 Pennhurst residents cites the following cost estimates:

	Institutional Costs	Waivered (Non-institutional Costs)
1983/1984	$44,584	$43,384
1985/1986	$47,209	$46,855

For the first year for the waiver, non-institutional services are expected to "save" $1,200 per client. During the second year, the "savings" are projected to be $354. These expenditure estimates for community programs, however, do not include the costs of room and board. Obviously, for this target population - which is representative of developmental center residents nationally - the total costs for community placements exceed the costs of ICF-MR care.

7. New York State and AFSCME collaborated to obtain $224,000 in Federal Developmental Disabilities funds with which to train institutional direct care and supervisory staff for new jobs in state-operated community-based programs. Since 1978, the State of New York has operated, and continued to expand, its publicly operated system of community ICF-MR's and group homes.

In Massachusetts, the State Legislature has earmarked 60% of all capital expenditures in mental retardation for state-operated, community-based programs.

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March 15, 1984

The Honorable David Durenberger
Chairman
Subcommittee on Health
Senate Finance Committee
219 Dirksen Senate Office Building
United States Senate
Washington, D.C. 20510

Dear Mr. Chairman:

The American Psychiatric Association, a medical specialty society representing over 29,000 psychiatrists nationwide, is pleased to provide our comments on the Community and Family Living Amendments of 1983, S. 2053. We are joined in this testimony by the American Academy of Child Psychiatry, an association of 3,000 child psychiatrists each with two years of training in an advance program of child psychiatry after completing a general psychiatry residency. We request that these comments be made part of the Subcommittee's February 27, 1984 hearing record on this legislation which would phase out Medicaid funding for residential facilities serving more than six to nine disabled persons while entitling such individuals to receive a wide array of home and community-based services.

The first objective of the American Psychiatric Association is to "improve the treatment, rehabilitation and care of the mentally ill, the mentally retarded, and the emotionally disturbed." As such, we have been deeply concerned and committed over the years to meeting the needs of those articulated populations -- particularly the most chronically mentally ill and retarded. We fully support the intent of the Community and Family Living Amendments: "the full participation of severely disabled individuals in community and family life" and have long articulated the need to provide appropriate levels of insurance coverage to enable these individuals to be treated for their medical illnesses enabling them to rejoin the producing, contributing national workforce. Improving the lives of disabled Americans -- whether physically or mentally impaired -- without question should be the goal of Congress, as it is the medical profession's, in particular. However, the intent and end result of the proposed legislation would differ markedly, were the legislation to be enacted as written.

The provisions of S. 2053 are based on arbitrary size limitations and judgments regarding the needs of the mentally disabled, and supported by questionable cost analyses and interpretations of major studies relating to deinstitutionalization.

For these reasons, articulated in greater detail below, we must oppose enactment of S. 2053 as written. Many questions remain unanswered; many details remain confused. The experience of current Medicaid community and home-based care waivers might more appropriately serve as a guide to future legislation, particularly given the serious and tragic problem which befell countless of the chronically mentally ill when they were deinstitutionalized en masse beginning in the mid-1950s.

In 1955, there were 600,000 patients in the nation's mental hospitals. At about that time, the move to deinstitutionalize patients began. It stemmed partly from civil rights issues and a growing emphasis on personal freedom. It was also believed that community programs for the mentally ill were more humane and effective, not to mention cheaper than the so-called warehouses for the mentally ill, often with populations nearing 5000 in some facilities. Unfortunately, those community programs were inexpensive indeed, they were nonexistent. Thousands of the chronically mentally ill flooded communities when state after state sought to close the institutions without the corollary commitment of funds to support adequate community services. Many of these people, unable to live independently, were forced into substandard boarding homes or shelters for the homeless. The Congress learned a number of years ago about SROs (single room occupancy) and the plight of the thousands of mentally ill living in the half-world of such facilities. More recently, the nation has similarly turned to look at the homeless. A recent Little Hoover report from the state of California has disclosed the very same pattern of disregard for the disabled and elderly which had been leveled against larger institutions to be present in the now-burgeoning board and care facility industry in that state which has yet another repository for the deinstitutionalized mentally disabled and elderly.

Caring psychiatrists, other physicians and health and mental health personnel coupled with a small, but growing number of the patient and parent support organizations are still seeking means of combatting the stigma of mental illness which reduces the community concern or activity. They are still scrapping for dollars to support this community network which was to have been in place when the movement began. They are seeking, at the same time, to maintain a full spectrum of care settings, whether larger or smaller, whether "institutional" or "community based" (a misnomer about which we will speak later), which can best meet the particular needs of each of the chronically mentally ill of our nation.

The message which emerges from this painful history lesson is that deinstitutionalization is good in theory, good for some in practice, but absent proper planning, data bases, personnel bases, community support and, indeed, money, it is fatally flawed. We are concerned that as written, S. 2053 contains many of the same pitfalls and holds out the same altruistic hopes as did the deinstitutionalization movement for the mentally ill.

WHO WOULD S. 2053 TARGET FOR "COMMUNITY" SERVICES?

Medicaid now provides for the health care needs of at least the financially indigent of all participating states. Many states have broadened that population to include the medically needy. Among those persons are mentally disabled individuals meeting the Medicaid state-Federal criteria. That program supports medical treatment, whether institution based or community based for the eligible population. (Mentally ill individuals, though financially eligible, are excluded from Medicaid coverage for hospital based care if they are between the ages of 22-65.)

Today, the Federal share of Medicaid funding is being reduced. States are being hard-pressed to provide sufficient resources to meet the current agreed-to coverage for those now eligible for the program. The legislation before the Committee proposes to broaden at least one segment of the population -- the mentally retarded -- who will by Federal statute -- not state decision-making -- be eligible to receive Medicaid funding for health and other services (some of which have not traditionally been Medicaid funded). But utilizing the definition from the Developmental Disability Act to form the basis for the population to be covered, the legislation would expand Medicaid coverage to essentially all mentally impaired persons who may or may not now be living in the community the onset of whose illness occurred by age 22. The legislation proposes to broaden the population further, by encompassing individuals for whom onset of the disability occurred prior to age 50. As noted, it becomes irrelevant whether that person is residing at home or in an institution at this time. Thus, persons eligible for the services, by Federal statute, would include not only those now institutionalized with an illness onset at age 50 or lower, but those now residing successfully in the community who otherwise might not be Medicaid eligible. The legislation is creating a new mandatory category of "medically eligible" individuals (now included under Medicaid at state option) who must receive community-based care. The provision extending Medicaid services to the families of severely disabled children, if the family income exceeds the eligibility criteria, is needed. However, the five percent of income spent on disability services does not give an adequate sense of the effect the provision would have on the family or on Medicaid expenditures. Last, the measure would extend, by option, to mentally ill persons, whether they reside in the community or in institutions at the very time Medicaid has never provided hospital-based care to the same population between the ages of 22-65.

Medicaid will be paying substantially more to provide a myriad of services -- some now not available for Medicaid eligibles. Funding availability aside, there is a serious question as to whether the service network necessary to support such a population actually exists or could exist in a community. It would support housing, rehabilitation, vocational activities, health care, and daily living care for a population as varied in level of care requirements as can be imagined.

FACILITIES VERSUS COMMUNITY

S. 2053 makes the argument that "community" is better than "facility." It would limit Medicaid payments to eligible individuals residing in a "community or family living facility" with a capacity no greater than three times "the number of persons in the average family household in the area in which the facility is located..." As the average family household in the U.S. generally runs between two and three, the maximum size of a community or family living facility would be six or nine individuals. The current literature offers no convincing evidence to support the premise that independent living skills can be taught only in certain-sized facilities or that given the same individual care -- which can be and is the case in any number of what the bill would consider to be "institutions" -- developmentally disabled persons progress better in smaller than in larger settings. (See for example Baroff, "On 'Size' and the Quality of Residential Care: A Second Look," 18 Mental. Retard. 113(1980) or Brown & Buard, "The Treatment Environment for Retarded Persons in Nursing Homes," 17 Mental. Retard. 77, 79-80 (1979).)

Community placement is ideal for many developmentally disabled persons but not all. It is a cruel but avoidable fact that many institutionalized retarded persons are multiply handicapped, also suffering from blindness, deafness, cerebral palsy, epilepsy, or other disorders. For patients such as these, a program of habilitation may well require a complex array of professional services -- including not only good care and medical treatment, but also language or speech therapy, physical therapy, feeding, behavior training, and occupational therapy -- which often are available only in institutional settings. Other patients are so agitated, self-abusive or violent or otherwise present such behavioral difficulties that some restrictions or intensive therapy are needed. The APA strongly defends the right of such patients to institutions, as well as the humaneness of their being served there.

This position is in no sense an apology for inhumane institutions. In our view, if the right to habilitation is recognized, comparable high quality humane care and habilitation must and can be provided regardless of whether or not it is in a setting deemed an "institution." We believe that state and other facilities of a size larger than envisioned by this legislation should remain available as an option for appropriate patients. S. 2053 forecloses this option.

As Throne has observed "The distinction between institutions and communities is a false one. A human community is composed of people and their institutions.... Small and medium sized community-based residential facilities, group homes, and foster care homes are institutions too.... The issue is not one of Institutionalization versus deinstitutionalization.... The issue is what kind of institutions best serve." (Throne, "Deinstitutionalization: Too Wide a Swath," 17 Mental. Retard. 171 (1979)) S. 2053 prohibits a response to that issue by closing some facilities which might "best serve" some of the developmentally disabled.

COST

It is argued that this legislation will save Medicaid funds now expended for institutional care. It is argued that this legislation will save many of the developmentally disabled from lives lacking in habilitation, lacking in treatment. Both are patently false for a number of reasons:

(1) Medicaid requires "active treatment" to occur in all facilities now providing care for the disabled. That active treatment could be equally flouted by larger institutions or smaller facilities which spring up as the result of the board and care industry this legislation will set in place.

(2) As has been noted, the population base is appreciably larger than current Medicaid beneficiaries who are developmentally disabled. Even if "community care" costs less per capita, it will ultimately cost far more than current Medicaid pays for those now under the program.

(3) Economies of scale do not exist, particularly in meeting the needs of the disabled for physical therapy, and other forms of therapy routinely provided in so-called institutions.

(4) Saved Federal Medicaid dollars will be more than offset by State dollars utilized to provide care to those profoundly disabled who are not candidates for community-based treatment and to provide care for those persons whose needs require institutional care when "necessary" care fails.

(5) Substantially greater Federal dollars will need to expended to expand appreciably the programs under P.L. 94-142 (Education for the Handicapped Act) which would be required to meet the educational needs of those newly returned to the community -- many of whom would be among the most profoundly disabled of the population.

(6) Cost estimates about community-based care reflect the costs associated with those now being treated in the community, not those who remain in institutions. The latter are in greater need of a large constellation of medical, social and rehabilitation services than the former.

(7) Capital outlays for this legislation are unknow, but estimates are already in the billions. Coupled with the cost of services, construction and rehabilitation of facilities for

community-care for this population far outstrip the modest estimates of the bill's cost. An example of the problem that can result in the rapid development of community care is the 1974 CHAMPUS problem, when it was discovered that children and adolescents were being sent to residential centers of all sizes and qualifications. Federal money was being used to provide totally inadequate treatment because facilities were needed so rapidly the controls broke down, or were never in place. The recent California Little Hoover Commission Report (December, 1983) bears out our concern that both a new "industry" could be created by this legislation, and that existing monitoring cannot today keep up with the needed certification and review of such facilities.

It appears to us that what this bill represents is an interesting way to seek adoption of a program which requires substantial Federal, state and local funding in a time of severe economic constraints by premising its adoption upon the phantom availability of Federal-State dollars (through the troubled Medicaid program) to pay its way. Given economic realities, however, we are deeply and seriously concerned that what will be created is yet another example of the failure of deinstitutionalization as the result of absent resources. We cannot afford another example of what we still are trying to resolve for the mentally ill happen to the mentally retarded.

The APA believes that Congress should not proceed with this legislation until many of the questions about appropriate care setting, service availability, financial resources, and population to be served are answered clearly. The ongoing experience under the Medicaid Community and Home-based care waivers may provide some greater evidence. We hope the Committee will work with us as we mutually seek answers to these questions as well as those posed by the failed past deinstitutionalization movement which has affected the mentally ill.

Respectfully Submitted,

George Tarjan
President, American Psychiatric
Association
Past President, American
Academy of Child Psychiatry

GT/TF:mm

Arkansas
Association of
Human Development
Center Parents

TESTIMONY

ON

COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983, S. 2053

FOR

SENATE FINANCE SUBCOMMITTEE ON HEALTH

Senator Dave Durenberger, Chairman

February 27, 1984

Prepared by: Missie Rasnick, President
Arkansas Association of Human
Development Center Parents
1105 Eastwood Drive
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Summary - S. 2053
By: Missie Rasnick

February 27, 1984

Senator Durenberger and members of the Subcommittee on Health, I welcome this opportunity as a counselor, teacher, parent, and advocate to speak for myself and thousands of fellow Arkansans in opposition to "The Community and Family Living Amendments Act" now S. 2053.

Our major concerns resulting in this consensus follows:

I. Medicaid Restructuring Is Needed . . . but S. 2053 is not the vehicle for doing so, since the ultimate outcome for Arkansas would be the closure of all eight of our ICF/MR facilities serving approximately 1,400 clients. A population which is 99 per cent Title XIX eligible. Maximum reimbursement rate of 72 per cent eligible costs are realized. The Arkansas taxpayers, with a present 10.5 per cent unemployment rate, low wages, and recent raised taxes to support education, could not generate enough revenue to replace the Title XIX dollars S. 2053 would take away from our institutions. The first just began operation in 1959 and their demise would create a crisis for Arkansas.

It would be impossible to have alternate services, meeting Federal guidelines, within the time frame mandated by S. 2053. Why must it be "one versus the other" instead of a continuum of services. Why not maintain quality institutions as an alternative? Since for many, this is their real home in the least restrictive environment.

II. The Lack of Learning From Past Mistakes. When advocates began lobbying to "set the mentally ill free" and "give them their rights" as well as "save taxpayers dollars", the result of such action has produced hordes of street people whose populace is much younger with thousands of women. In the past 20 years, over 800 chronically mentally ill patients have fallen through official fingers into Arkansas streets and boarding homes, many of them unfit. Dr. Robert Shannon, State Mental Health Commissioner, commenting on S. 2053 stated that unless policy makers in the field of Mental Retardation profit from the documented examples in the mental health field, the mentally retarded could join the mentally ill, the out of work and the alcoholic derelict in the nation's streets, alleys and bus stations.

In reference to the aforementioned comments, I trust that they have helped clarify the reason that so many people are opposed to the "Community and Family Living Amendments of 1983", S. 2053.

S. 2053, DISASTER FOR ARKANSAS SERVICES

Arkansas was the forty-seventh state to develop a state school for developmentally disabled children. In Conway, Arkansas on October 4, 1959, the Arkansas Children's Colony was formally dedicated.

This unit is now one of six Human Development Centers, Easter Seal Center and Mickel's Infant Infirmary, all ICF/MR facilities that serve approximately 1,400 developmentally disabled persons, of all ages, in Arkansas.

The Booneville Human Development Center, Booneville, Arkansas, where my twenty-nine year old severely retarded daughter resides, like all of the other Centers in the state, is a model that it might be well for other service providers to observe and copy. This institutional setting is atop a beautifully landscaped hill among the pines. It has dormitories with single rooms for each resident and full time supervision; group homes with varied degrees of supervision; and single family dwellings for two to four occupants that need a minimum of supervision.

Many of these people are able to go to work, shop, prepare their own meals, participate in vocational training, social activities, and sports events which may be on or off campus. (Exhibit I, Booneville H.D.C. Special Olympics).

The primary objective of this Center is to provide a program to all of the residents, with emphasis on life survival skills, so, where possible, they may seek a life away from the institution. During its ten years of existence, 255 residents have left the Center to reside in group homes; with their respective families; in rehabilitation centers; in foster care facilities or apartments. Many have made the transition successfully, but some have not. The lack of success is often due to the fact that during a difficult adjustment period, these developmentally disabled persons displayed behavior that the community providers would not tolerate. As a result of these actions, the person involved has ended up on the streets, in jail, or back in intolerable home situations. This situation should be corrected, since how many so called normal people, suddenly thrust into a totally different life style among strangers, can make the transition without emotional trauma. It is difficult enough for these so called normal people who possess a far greater reasoning ability to make decisions and predict the utility of the action than the mentally retarded person. Yet, there are those who expect the mentally retarded person to adjust to such a situation in a matter of days or weeks. Why not maintain quality institutions as an alternative? Since for many, this is their real home. When the mentally retarded person is forced into a situation beyond his or her ability to adapt, it often results in displays of bizarre behavior (Exhibit II, "Sunland").

A young woman left the Booneville Human Development Center to live in a group home, she soon progressed to marriage and giving birth to a baby. The constant demand on her time to care for the baby and its incessant crying caused her to reach a breaking point. One day she grabbed a pan of boiling water from the stove and used it to scald the baby to death. This young woman is now in a prison in Arkansas, the victim of a situation beyond her control. Reports of rape, pregnancy, suicide, public appearances in underwear, public disturbances, venereal disease, drowning, and disappearances are just some of the fates awaiting many retarded who are released from the institution for independent living without the proper followup by a case worker. Case management must have top priority in any move toward deinstitutionalization.

My daughter, Susan, was the recent subject of an editorial by Jack Moseley in the Southwest Times Record, Fort Smith, Arkansas after he had studied the "Community and Family Living Amendments of 1983", now referred to as S. 2053. Part of his Letter From the Editor" read like this: "Goals great, but what about realities? She's twenty-nine years old and very happy. She has a boyfriend and enjoys the companionship of those around her. She feels secure and free to walk across the green meadows or rest in the shade of tall pines. When she visits her family she wants to get back to the place she considers home. But there are those in our society who want her to be more "free and independent". To achieve that well-intentioned goal, they would uproot this young woman, take her away from familiar surroundings, away from friends and make her part of a social experiment that in some instances actually has killed people. She and those who love her face the difficult task of opposing a growing national movement that sounds extremely appealing and humanitarian. Unfortunately, the practical side of this movement is packed with peril for the objects of social change."

Realizing that small and medium sized community-based residential facilities, group homes, foster homes and even the household of the conventional nuclear family are institutions; S. 2053 cuts too wide a swath since its blade threatens any institution except the one the supporter of S. 2053 chooses to defend. All of our ICF/MR institutions in Arkansas could be brought under this ax for one reason or another. When deinstitutionalization, in the form of a Federal mandate, attempts to force all mentally retarded citizens into a specific setting, regardless of prevaling conditions, it is not scientifically or morally sound. Research shows that with the proper use of operant procedures one can teach retarded people a multitude of skills, dependent upon their abilities, in any or all of the institutional settings mentioned above.

This issue started some years ago after money became available for research in the form of studies, travel, experiments, etc., and modern science produced drugs that in proper, regular amounts made some mentally ill people behave normally, whatever that is. Advocacy groups sprang up around the country and immediately began lobbying on behalf of the "rights" of the mentally ill. "Set these people free", they demanded. "Give them their freedom; give them their rights, besides it will save taxpayer's money."

State after state did just that. An article "Homeless in America" appearing in January 2, 1984 issue of Newsweek stated: "The people who pass the night in such accommodations as overnight shelters, phone booths, cardboard boxes, garages, abandoned buildings, over hot air grates or under bridges, are a much more diverse lot than in the past and much younger, now averaging in their low 30's. Twenty years ago the homeless consisted almost exclusively of alcoholic skidrow men, mostly white males. They have been joined by huge numbers of released mental patients, who now make up one-third to one-half of the total, and have added thousands of women to the streets. It's hard to tell who were seriously ill before becoming homeless, and who were driven over the edge by the rigors of street life. As states emptied overcrowded and ill-staffed hospitals, they set thousands free to fend for themselves. And now, as local governments and charitable organizations stretch to provide relief, they find, according to some accounts, that the more they do, the more they increase demand. Meanwhile, what they cannot do--from providing underwear (an item, unlike overcoats, that's rarely donated) to finding family backing and permanent housing--is what the homeless often need most (Exhibit III, "Life").

Because they live without addresses, the homeless are unable to receive food stamps and welfare in most states. Estimates range anywhere from 250,000 to two million nationwide, tens of thousands of whom hazard the elements every night."

The state of Arkansas is well aware of the plight of its mentally ill residents. Recently, the Little Rock Arkansas Democrat ran a series of articles on the "Boarding Homes for the Mentally Ill".

An editorial dated December 16, 1983 exposed the shameful condition and what brought it about. In part, it read: "Whose mental health? The State Department of Mental Health tells us that over the past 20 years as many as 800 chronically ill mental patients have fallen through official fingers into Arkansas streets and boarding homes, many of them unfit. The figure is probably even larger and State Mental Health Commissioner, Dr. Robert Shannon, admits to the Democrat that all these people and others since dead have been "cheated" and are probably even worse off than in the 1969's when the mentally ill were housed in Arkansas' medieval mental institutions. Shannon, also, states that unless policy makers in the field of Mental Retardation profit from the example in the mental health field, the mentally retarded could join the mentally ill, the out of work and the alcoholic derelict in the nation's streets, alleys and bus stations. This comment was made in regard to Shannon's concern for S. 2053.

"At this time, Arkansas' Governor Bill Clinton, legislators and concerned citizens are working to get funding for a long term care facility back on the State Hospital grounds and provide more supervised care for the mentally ill wherever they can be found."

"The plight of the people in the boarding homes is the product of the noble drive for 'deinstitutionalization' but no one intended that people released from institutions should end up wandering the streets, eating out of carbage cans and wasting away in unfit boarding homes which degenerates to mere existance because there is no other place for them to go."

Arkansas is a small state in area and is not heavily populated; therefore, it is simple to garner facts as to what has happened in the past and is continuing to happen to the mentally ill. It is for this reason that so many people are well aware of what happens when mass deinstitutionalization takes place. Due to the array of authenticated data from Life, Newsweek, Reader's Digest, newspapers, and other sources of information including on site observations, from around the nation; we have every right to believe, beyond a reasonable doubt, that the same fate awaits the mentally retarded in Arkansas and across America if S. 2053 should become an enforceable law now or ever. In fact, many states are already seeing some of their mentally retarded living as "street people".

I am president of the Arkansas Association of Human Development Center Parents; coordinator, Arkansas Parents' Network; board member, National Congrees of Advocates for the Retarded; president, Human Development Center Supporters; member, Developmental Disabilities Advisary Council; member, Governor's Commission on People With Disabilities; past president and secretary of local ARC's in Arkansas and Virginia; certified reading clinician having taught the mentally retarded for twenty-eight years and a secondary school counselor presently teaching and counseling retarded students and their parents as well as "normal" students with mentally retarded parent or parents. Most importantly, my claim to being an authority in the field of mental retardation is the fact that I am the mother of a severely retarded Down's Syndrome daughter.

As I have served in the many capacities associated with mental retardation, other vital concerns about the Federal legislation titled "Community and Family Living Amendments of 1983" now Senate Bill 2053 have come to my attention. These concerns have come from many sources such as parents, service providers, legislators, business leaders, Developmental Disabilities Board members, Human Services Administrators, Arkansas State Department of Education representatives, and other interested citizens, Exhibit V "Third Congressional District Caucus Resolution". Some of these concerns are:

1. Medicaid restructuring is needed but S. 2053 is not the vehicle for doing so, since the ultimate outcome for Arkansas would be the closure of our institutions.
2. These concerned people are completely committeed to the philosophy that a continuum of services is needed, ranging from home to institutional care, with as many incremental options in between as necessary with no time frame attached to providing services.
3. There is a consensus that community options are not available. To provide this wide array of services, we must accept the responsibility of working together for the development, implementation and retention of the alternate services. We cannot let S. 2053 cause us to be "pro-institution and anti-community based" or "pro-community and "anti-institution based" service advocates.
4. If S. 2053 were passed and enacted into law in its present form, the phase down of Arkansas' institutions could begin within six months and be totally phased out long before the maximum ten year period elapsed.

   It would be economically impossible for Arkansas to have alternate services (that meet Federal guidelines) available for the 1,280 clients of the ICF/MR facilities within the time frame defined in S. 2053. Ray Scott, Director of the State Department of Human Services, agrees that were the Federal government to decide that at some effective date Title XIX funding was to cease for the institutions" then it would be a crisis in Arkansas.

What Scott sees happening is a series of things being done that would result in Congress, for example, devising a different funding rate for institutional based services, compared to community based ones. He doesn't foresee the "either or" situation described by Ms. Myrl Weinburg and the National Association of Retarded Citizens which maintain that both institutions and community based services cannot be funded and afforded so the institutions must go.

Dr. Ray Nelson, Commissioner, Developmental Disabilities Services, stated that Arkansas cannot completely move away from institutional models. A certain amount of institutional care will continue to be needed.

Proponents of S. 2053 say it is not devised with the intent of forced closing of the institutions but it would definitely cause this to become a real situation in Arkansas. The taxpayers of this state could not generate enough revenue to replace the Title XIX dollars taken away from our institutional programs. At this time almost 99% of our ICF/MR institutional population is Title XIX eligible. Maximum reimbursement rate of 72% of eligible costs are realized.

5. Arkansas has one of the highest rates of teenage pregnancies in America. These pregnancies are producing a high incident of infants with birth defects. This situation alone is creating a need for services which will call for increased revenue at a time when the Federal government is cutting Medicaid funding to the bone. S. 2053 expects the state to magically produce dollars for these services but they are just not there. Birth defective children of mentally retarded females, also, remain as a tremendous problem in Arkansas. Human Services can place the physically sound babies out for adoption but it is the responsibility of the family or friends to try to secure help for the defective ones. If S. 2053 were passed, it could mean that facilities such as Mickel's Infant Infirmary, Clarksville, Arkansas, an ICF/MR facility (the

only one in the state), that cares for newborns would lose its funding and cease to operate. Many of these infants will always be medically involved and not be capable of functioning or even not continue to live on God's earth without the intense medical supervision necessary for the sustaining of life that Mickel's provides them. For some other infants who receive Mickel's intensified program early in life, a successful integration back into the community is possible (Exhibit IV, High Risk Pregnancy).

6. Arkansas unemployment rate rocketed to 10.5 per cent in January and Governor Clinton stated that many counties had unemployment rates of 16 to 20 percent.

   S. 2053 states that due to technological advances the severely and profoundly retarded can become self-supporting. This claim is totally without scientific proof. However, there are some of the higher level mentally retarded clients being trained to leave the institution and become self-reliant if they could find a job. Due to the shortage of jobs, large numbers of Arkansans seek the available ones paying minimum wage; therefore, the mentally retarded cannot compete in the job market. If they are pushed out to fend for themselves, could they become nothing more than targets for slave labor or an even worse fate.

7. Arkansas has the "right to work" law and state employees are not unionized. S. 2053 states that a union representative from each state will negotiate with the "Secretary" to secure comparable job placements for all institution employees and acquire some other "business" for the facility when it is phased out.

   When community leaders of Booneville and other towns and cities around Arkansas became aware of this situation they rallied to our support in the defeat of S. 2053. The Booneville Human Development Center is the largest unit that generates jobs in this area. People work at this Center from several adjoining counties. The loss of their jobs would be a loss in state tax dollars too. These tax dollars are needed to generate the Title XIX funds so this would deny services wherever they might be located. Most of these people would not be willing to work in a prison or have one in their community and it would be a likely consideration for such a facility in this unit as it has been considered strongly in the past.

8. Arkansas has and is currently engaged in the process of upgrading public education, and the citizens are paying a "high price" to do so. Forcing the severely and profoundly mentally retarded children into regular public school settings will demand far more educational tax dollars and often times produce nothing more than a life threatening situation for the student. As an educator, I can tell you this is not what education is about. It will only help generate opposition to the mentally retarded who are already being served since the children who can actually be educated to carry on the affairs of the community, state, nation, and world will suffer from such action. Also, as a parent of a severely retarded child, neither I nor other parents with whom I have discussed this issue want it for our children.
9. S. 2053 could take away from the individual state governments their right to secure and dispense "Medicaid dollars" to the best of their ability. In fact, if it comes into the state as "open ended" dollars, it could very well be up for grabs" by the most powerful interest groups. It could very well never be used to provice services for the developmentally disabled, regardless of whether they are residing in a community or so called institutional setting unless their advocates are one of the powerful interest groups.
10. S. 2053 is unacceptable due to Section 6 as it establishes a mandate for litigations that could result in advocate lawyers and a few clients destroying the fine programs we have in the state of Arkansas and the denial of services to those who often times need it worse. The courts should not make program decisions. I have seen the results first hand in Florida, Texas, Pennsylvania,

> Kentucky and Nebraska and have heard of similar results in Massachusetts, Connecticut, and New York when advocates, such as state affiliates of ARC-US, brought suits to close state schools and the devistating affects of such actions. The agony suffered by both parents and clients of the schools are untold yet the movement goes on. Death, broken homes, broken hearts, and broken bodies have had no impact on the social planners who so often get the "cart before the horse." The money and the community facility must be in place before the client is moved from the institution. Then, the institution must remain as a viable option for those who need it for the rest of their life. Title XIX money, must not be used as a ploy to simply implement a total new concept of care without further research and planning.

From the foregoing comments, I trust that some of the points clarify the position taken by so many people in opposition to Community and Family Living Amendments of 1983, S. 2053.

I, also, wish to pledge myself and many Arkansans to work diligently with others to draft and support an alternate version of the Community and Living Amendments of 1984. We do realize that development and funding of alternatives to institutionalization must be done now or in the very near future.

From what I have been able to study, the New Jersey alternative draft version of the Community and Family Services Amendments of 1984 may be the document, already conceived, from which we can begin discussions.

EXHIBIT I

OPENING CEREMONIES—Members of the Booneville Human Development Center march as a unit in the opening ceremonies of the Olympics. The various groups took part in this march down the track and vowed to "be brave in the attempt."

A light rain failed to dampen the enthusiasm of the volunteers, spectators or participants at the Area 14 Special Olympics Saturday at Bearcat Stadium.

The competition saw a record number of participants who were competing in the athletic tests with no losers. The beauty of the Special Olympics comes just from being a part of the program.

Most of those who sat through the drizzle during the morning came away with an appreciation of the meaning of courage.

Most of the volunteers and spectators who were not participating were able to understand the meaning of the Special Olympics.

That meaning is exemplified in the motto:

Let me win, but if I cannot win;
let me be brave in the attempt.

EXHIBIT II

Doctor says Sunland residents misplaced

By Rosemary Goudreau

OF THE SENTINEL STAFF

Mentally retarded people who are sexually violent, carry contagious diseases or have life-threatening medical problems were placed in an Orlando neighborhood facility not equipped to take care of them, their doctor says.

One 11-year-old girl faces imminent death from a mysterious virus she caught at the new nursing home for the retarded. She lived 9½ years in Orlando's Sunland Center. Twenty-four hours after being moved, she contracted the virus that is killing her, the doctor said.

The child is one of five people the home's medical and nursing staff say should never have been taken out of Sunland and placed in their home.

But in the rush to empty Sunland centers in Tallahasse and Orlando, the home's staff said that state health officials are pushing the retarded around like paperwork, with little attention to some of their special needs.

The 1979 Legislature ordered that the two Sunland centers be closed for safety reasons. Both are multistory, former tuberculosis hospitals that would be fire traps to retarded people who cannot walk or even realize danger.

Sunland residents with medical problems are being moved to 64-bed intermediate care facilities or 24-bed cluster homes being built around the state. Those able to help themselves are moving into community group homes. Retarded infants are going to

Please see **SUNLAND, B-7**

SUNLAND

From B-1

foster homes.

But determining the best housing for some individuals has created problems for the retarded and those taking care of them.

Since an Orlando-area intermediate care facility opened in July, Dr. William Musser of Maitland said five people have been sent there that his staff could not be expected to handle.

Department of Health and Rehabilitative Services officials said they hope to eliminate some of the transfer problems by improving communication between the Sunlands and the receiving homes.

But according to HRS rules and guidelines, officials said the local facility should have been an appropriate place for the following five patients:

- A violent retarded man known to have broken another patient's leg at the Gainesville Sunland Center. Since his arrival last month, he has punched an aide in the face, threatened a nurse with a jagged piece of glass, and was found disrobed in a female patient's room, apparently ready to rape her.

He frequently wanders away because the home is not allowed by law to lock him in. Arrangements are being made to transfer him to a secure facility.

- The 11-year-old girl whose medical history includes chronic viral and respiratory infections, uncontrollable fevers of 105 degrees, dehydration and a condition requiring a nasal tube for feeding.

However, HRS officials decided she did not need an intensive care facility. Since contracting the virus, she has been near death in an area hospital.

- Two brothers from the Gainesville Sunland who were hepatitis carriers. The staff feared other patients would catch the contagious disease. So when a van driver from Gainesville brought more patients, the staff packed the brothers in the van and sent them back.

- A young girl whose test for tuberculosis ca back positive. Although a radiologist said X-r showed her lungs were clear, and although Orange County Health Department officer said s was not contagious, the doctor was told to kee close eye on staff members working with her.

Staff members remain uneasy about the possi spread of the disease.

- A boy from the Orlando Sunland who has severe bladder obstruction that prevents urinati His medical history includes kidney disease, rec rent urinary infections and urine retention.

State officials say these cases are isolated pro lems in a new program that needs community acce tance. They say there are many more examples retarded people receiving better care, extra atte tion and more privacy in the new homes.

Intermediate care facilities have opened in Sou Seminole County, Jacksonville and Tallahass Each houses 64 retarded people in a cluster of fo ranch-style homes.

The staff of the local, privately-run facility agre to talk about transfer problems only if *The Orl Sentinel* agreed not to pinpoint their home's loc tion. They said that while they are working wi HRS to correct the problems, they fear their neig bors would not understand.

Their home is licensed to care for retarded peopl who cannot walk or who have minor medica problems.

Staff members met twice during July with HRS officials to ask that no more medical or violent case be sent there. Three cases — the dying girl, the gir with a positive TB test and the boy with trouble urinating — were reviewed.

Joyce DeFlippo, one of many supervisors for portions of the transfer plan, and other state officials agreed the violent man should not have been placed in the home and arrangements are being made to transfer him back to Gainesville's Sunland.

Life, May 1981

EXHIBIT III

As a child, Rich Berard claims, he was mistreated. Heavily into drugs as an adolescent, Berard *(below, center)* has spent the past nine months on the sidewalks and in the coffee shops of Springfield, Mass. He is 24. A former NSH patient, he lives in a church-funded rescue mission. He sees a doctor and plans to attend a day-care clinic. In that respect he is lucky. Sixty-five percent of the Springfield residents in probable need of psychiatric care get no help from any program. Many inhabit the city's old hotels and alleys. Says one boardinghouse proprietor, "The cops literally dump 'em on our doorstep and say, 'You handle 'em.'"

Most days, Berard divides his time between restaurant lounging and harmless street-corner antics (above). Three dollars provides him with two meals and one of nine mattresses on the mission's chapel floor (below). He often refuses medication since his roommates are not required to take any. Others call him "Butterfly" because of his fitful trembles and blinks. "I'm always alone," he says.

EXHIBIT IV

High-risk pregnancies, births show increase in Arkansas, nation

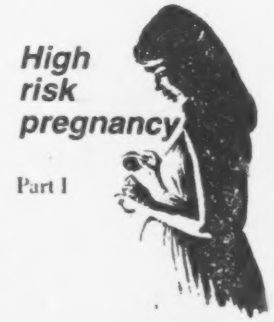
By TED JACKOVICS

Democrat Pine Bluff Bureau

JONESBORO – Kaye Williams won't forget the two times she met an internationally renowned professor of child development from California.

About three years ago, Mrs. Williams complimented the professor on a speech she made about factors that lead to mental retardation and other disabilities.

This is the first of a five-part series on high-risk pregnancies and births in Arkansas.



"Then I told her Jonesboro didn't have those kinds of problems," Mrs. Williams recalled.

The two women met again earlier this year.

"This time I was not so smug," Mrs. Williams said.

And for a good reason.

These days, she spends her time counseling people like 14-year-old Suzy, who tried to hide her pregnancy by dieting and gave birth to a child that died after three weeks.

As co-coordinator of one of the state's pilot parenting education programs, Mrs. Williams is well versed with the problems of the approximately 10,000 annual high-risk births which touch the lives and pocketbooks of Arkansans.

Last year in Arkansas, more children than the student body at Arkansas State University were born either with birth defects, at a low birth weight or to mothers in their early teens or without husbands.

These children, because of their medical or social condition at birth, have the potential of becoming developmentally disabled, officials said.

To the dismay of people who believe many of the problems could be prevented (including, for example, 50 percent of all cases of mental retardation), high-risk pregnancies and births are pervasive in Arkansas.

Statistics from the nation's first count of high-risk infants, prepared specifically for Arkansas, show the following:

- The number of children with birth defects jumped from 286 in 1980 to 347 in 1981, about 1.1 percent of all births. The most serious defects, often associated with mental retardation, rose 45 percent in 1981 compared to 1980.

To deal with problems of child development, Arkansas is making a large investment.

More than 200 agencies that sponsor programs for developmentally disabled people, as defined by complex federal law, spent more than $200 million in 1980.

However, a closer look shows there is no overall strategy of prevention, early intervention and treatment to guide the myriad of services in Arkansas.

And officials believe many people who need services are not getting them.

The Developmental Disabilities Planning Council has responsibility for statewide planning, but has no authority to implement its plans, Director Mary Eddy Thomas said.

Agency officials with the same general idea about improving the lives of children are fighting behind the scenes for funds for individual programs as federal cutbacks have made money scarce.

And Arkansas, which attained national notoriety in the 1970s by ranking first among states in illegitimacy and teen-age pregnancy problems, is not the only state with problems of high-risk pregnancies and births.

A report issued in 1980 by the U.S. Department of Health and Human Services predicted that between 100,000 and 150,000 children born each year will be destined to be mentally retarded. Many of these children will have other birth defects, the report said.

A New York research agency published a report in 1975 that found the rate of deliveries among U.S. teen-agers – an age group susceptible to problems of high-risk pregnancies – was among the world's highest.

Only four industrialized countries – Romania, New Zealand, Bulgaria and East Germany – reported higher teen-age fertility rates.

And some people have said the nation's cities are being threatened with an epidemic of illegitimate children and its related problems.

EXHIBIT V

RESOLUTION

WHEREAS, Senator John H. Chafee of Rhode Island has introduced S. 2053 (Community and Family Living Amendments Act of 1983) in the United States Senate; and

WHEREAS, S. 2053 would provide monetary incentives to severely disabled persons to leave institutions and return to community settings; and

WHEREAS, S. 2053 would amend the Social Security Act to phase out Title XIX funds going to most institutions for severely disabled persons; and

WHEREAS, Senator Chafee has stated that S. 2053 would shift the federal share of Medicaid funds from institutions housing severely disabled persons to community-based integrated settings; and

WHEREAS, Senator Chafee has also stated that S. 2053 is designed to encourage states to reduce the number of severely disabled persons living in institutions by providing community living arrangements; and

WHEREAS, this proposed federal legislation would result in the closing of most institutions for severely disabled persons in Arkansas; and

WHEREAS, the closing of our institutions would result in virtually throwing our severely disabled citizens on the street; and

WHEREAS, S. 2053 is unconscionable and must not be enacted into law,

NOW THEREFORE,
BE IT RESOLVED BY THE THIRD CONGRESSIONAL DISTRICT CAUCUS OF THE MEMBERS OF THE SENATE AND HOUSE OF REPRESENTATIVES OF THE ARKANSAS GENERAL ASSEMBLY:

That the members of Arkansas' Congressional Delegation are hereby requested to seek the defeat of S. 2053 entitled The Community and Family Living Amendments Act of 1983.

Representative Frank J. Willems
Chairman
Third Congressional District Caucus

Apple Creek Developmental Center
Citizens Advisory Board
Resolution Concerning Senate Bill
2053

March 23, 1984

The Citizens Advisory Board at the Apple Creek Developmental Center, Apple Creek, Ohio, opposes the present draft of Senate Bill 2053, but supports legislation encouraging the increased development of family-sized residential facilities. This letter explains why we feel this way and offers some constructive comments on recommended changes for your consideration.

The Apple Creek Developmental Center is a 346 bed state operated developmental center for the mentally retarded and developmentally disabled. At one time, it was one of the worst facilities in the country. Now, because of court mandated compliance with national accreditation standards (AC/MRDD and CARF), it is considered to be one of the best facilities in the country and the turn-around has been remarkable.

Citizen Advisory Boards, established under Section 5119 of the Ohio Revised Code, have a monitoring and review function at state-operated developmental centers. Members serve without pay. Many of the members on the Apple Creek Developmental Center Citizens Advisory Board have had some involvement with trying to get small residential facilities established in the community. Some of the Citizen Advisory Board members are parents of mentally retarded and developmentally disabled children who are also served in community programs. We of the Citizen Advisory Board are concerned with service provision to this group of people and with long-range planning.

We agree that in general the mentally retarded and developmentally disabled are better off in small family-sized homes. We feel that many of the people now at the Apple Creek Developmental Center would do well in small community facilities (least restrictive settings) where they would be enrolled in community schools and workshops.

There is however a minority of residents at Apple Creek with severe behavior and/or medical problems that we do not feel can be appropriately placed in the community, at least at this time. Apple Creek Developmental Center serves as a place of last resort for problem people that community agencies have not been able to deal with adequately. There are approximately 5-10 probate admissions to ACDC each year of this type. We are convinced that smaller developmental centers may always be needed for this group of people.

For these reasons, we oppose those provisions in the Bill that would totally cut off Medicaid funding to all state institutions within 10 years (pg. 15 of the Bill); or which would limit the length of time an individual could stay in a Medicaid-funded facility only to two (2) years (pg. 2 of the Bill, line 31). How certain are the sponsors of this Bill that all waiting lists in community programs will be eliminated within ten years? How certain are the sponsors of this Bill that all community programs will stop excluding people and develop zero-reject philosophies? Where would a developmentally disabled person go at the end of the two year period when there is no one else available or willing to serve them?

There is another danger in setting rigid time limits to withdrawal of funding from the institutions; namely that people would be forced into the community before appropriate facilities and programs have been established for them. Our Advisory Board is particularly sensitive to this because as Ohio has reduced its institutional population from 10,017 in 1967 to below 3,000 in 1984, some serious questions have been raised about "dumping" in order to meet the rigid timetables set by the state. Several class action suits were initiated as a result of this overall policy.

The mentally retarded and developmentally disabled that have been placed out from the institutions thus far have been the higher functioning residents. Those remaining are for the most part lower functioning and may be more difficult to integrate into community schools and workshops.

While we adhere to the philosophy that family-szied units are most appropriate from the standpoint of normalization, we recognize at the same time that if a facility is family-sized, it may be too small to have the specialized staff of a larger facility to meet the complex behavioral and/or medical needs of a low-incidence population. A 6-8 bed group home is not necessarily better than a 32 bed residential facility with specialized staff and quality programs. Therefore, we do not endorse the rigid provision of restricting all Medicaid funded community facilities to those of "a number of beds that does not exceed the product obtained by multiplying 3 times...the number of individuals in the average family household" (pg. 6, lines 7-18), but believe very strongly that the effectiveness of a program cannot be measured simply by its size but by its ability to help others in the provision of quality services.

A somewhat larger facility may also be more cost effective and easier to manage. However, we recommend that the sponsors of this Bill seriously consider developing greater financial incentives to encourage the development of smaller, more home-like centers and not categorically set arbitrary limits that may otherwise shut down some very fine programs. Another way to encourage small residential facilities would be to cut down on the paperwork. We feel many small home operators now are not getting involved in Medicaid because they are afraid of the paperwork.

The Bill speaks of locating Medicaid funded community facilities in "residential neighborhoods" without defining the term (pg. 6, lines 19-31). The Bill fails to recognize that facilities larger than 6-8 beds are not favored by city zoning codes. Therefore anything larger than this is most likely to be built in an unincorporated area where there are no zoning restrictions. We suggest that the Bill incorporate language that provides that such facilities in unincorporated areas be built within a 30 minute radius of schools and workshops for the retarded. Without this provision, those with more severe seizure disorders may not be transported and will be denied adequate program and community services.

The Bill stipulates that community and family living facilities should not be "unduly concentrated in any residential area (pg. 8, line 14). We suggest that this language be made more specific to prevent litigation over the term by developers who may want to for example, place two 12 bed homes side by side in the same neighborhood. We suggest that you restrict the concentration of such facilities to "no more than one facility per block face", or no more than one facility in a 1/4 mile radius.

The Bill provides for "periodic independent monitoring or review of the quality of medical assistance provided" (pg. 8, line 20). The problem with this section is that it does not provide for reviewing aspects of the facility other than medical assistance. Nor does it suggest who is going to do the independent monitoring. Parents and consumer groups want to be involved in this monitoring and this issue should not be glossed over lightly.

Section G 11 (pg. 8, lines 26-34) provides for a "periodic review by a State agency, community and facility or provider of medical assistance". We strongly disagree with this language. It can be interpreted to mean that no one other than the medical doctor who has a vested financial interest in the facility needs to review the program. The State Department of Mental Retardation and Developmental Disabilities or its delegated agent should be reviewing whether or not the needs of the individual are being served. This responsibility should not be solely a function of the State Department of Health.

We suggest that the language in G iii be made more specific (pg. 9, lines 1-4). Instead of saying residents should have "access to appropriate social, educational and medical services...", say "should have access to appropriate social and medical services and should be enrolled in on-site programs in schools and workshops". Otherwise inferior services may be substituted.

On page 10, line 27, the language of the Bill proposes that all community or family living facilities be accredited by the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons or is licensed or certified by an appropriate state agency. The sponsors of this Bill are probably not aware that licensing regulations are minimal (approximately 200) as compared to 565 Medicaid standards and approximately 1,483 accreditation standards. Our recommendation would be that all programs should be licensed. All programs should either be certified or accredited since accreditation standards are approximately three times more difficult to meet than Medicaid certification standards. However, if a program is accredited they have a chance through "deemed status" to waiver any Medicaid survey requirements as long as their accreditation status is in effect. Accreditation should always be on a voluntary basis and there should be some incentive for agencies to extend themselves in a more difficult manner to improve the quality of services. This also would be a nice way to reduce the amount of regulations, outside monitoring by governmental agencies and unnecessary paperwork.

Referring to page 10 of the Bill, approval for licensure should have to be jointly shared with the Department of MR/DD and the Department of Health. Otherwise, you permit a situation where facilities are established inappropriate to the needs of the mentally retarded. An instance of this nature occurred this last year where a nearby private facility was granted a Certificate of Need by the Ohio Department of Health to increase to 240 beds despite the written opposition of the Department of MR/DD, the community Board of MR, and our Citizens Advisory Board.

The Bill provides that a parent or guardian may appeal the transfer of a family member to a facility where "the types of medical assistance specified in the community services plan developed with respect to such an individual are inappropriate or inadequate". We think there needs to be a definition of these terms since they have different meanings for parents or for facility developers. Moreover, the medical assistance could be fine, but there could be other reasons that the parent or guardian objects to a transfer where a hearing would be warranted. Parents will not be able to successfully contest a transfer (pg. 10, lines 4-26) unless some definition of what is appropriate is written into the Bill. Moreover, it should be provided in the Bill that any parent that contests a transfer should be furnished with a copy of the pertinent legislation. Otherwise parents with limited means unable to hire a lawyer may not be able to present their case.

Other comments that we consider relevant are that privileges of normalization should include but not be limited to living in a facility that does not look like a nursing home and which is not attached as a wing to a nursing home unless intended for senior citizens. Grounds of community living facilities should be landscaped. Individuals living in such a facility should be referred to as residents and not as patients.

We believe that in most instances residents should be placed in their counties of origin. This is important for two reasons: namely so that an individual can be close to his/her family and also because of the adverse effect on local county facilities that develops when most of the retarded in a large geographical area are concentrated into a small geographical area. The tax base of one county should not be forced to provide school buildings and workshops unreasonably related to the local need.

Approved 3/22/84.

STATEMENT SUBMITTED TO THE UNITED STATES COMMITTEE ON FINANCE, SUBCOMMITTEE ON HEALTH

IN SUPPORT OF S.2053

THE COMMUNITY AND FAMILY LIVING AMENDMENTS ACT

(FEBRUARY 27, 1984 HEARINGS)

ON BEHALF OF THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS

BY

THE WORK GROUP ON COMMUNITY LIVING AT SYRACUSE UNIVERSITY

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On behalf of The Association for Persons with Severe Handicaps (TASH) and the Syracuse University Center on Human Policy, we wish to express our strong support for S.2053, the Community and Family Living Amendments Act. We also want to offer our assistance to the Subcommittee on Health of the Senate Finance Committee in its efforts to improve the quality of services offered to citizens with severe disabilities.

The Association on Persons with Severe Handicaps is composed of 5,000 professionals and parents. Our membership includes not only university researchers, special educators, and community service professionals, but institutional employees as well. Based on its professional expertise and experience, our membership issued a policy statement that supported family-like community-based services for all people with severe handicaps:

> TASH POLICY
>
> To realize the goals and objectives of the Association for the Severely Handicapped, the following resolution is adopted:
>
> In order to develop, learn, grow and live as fully as possible, persons with handicapping conditions require access to services which allow for longitudinal, comprehensive, systematic and chronological age appropriate interactions with persons without identified handicaps.
>
> Such interactions must occur in domestic living, educational, vocational and recreational/leisure environments.
>
> Specifically, handicapped individuals should:
>
> 1. participate in family-like and/or normalized community based domestic living environments;
> 2. receive educational services in chronological age-appropriate regular educational environments;
> 3. receive training in and access to a wide variety of vocational environments and opportunities, regardless of functioning level; and

> 4. participate in a wide range of normalized recreational/leisure environments and activities that involved persons without identified handicaps.
>
> The Association for the Severely Handicapped believes that the above conditions must be met in order to provide quality service and that these conditions can only be met by community based services.
>
> THEREFORE, The Association for the Severely Handicapped resolves that it will work toward the rapid termination of living environment and educational/vocational/recreational services that segregate, regiment and isolate persons from the individualized attention and sustained normalized community interactions necessary for maximal growth, development and the enjoyment of life.

S.2053 requires the transfer of federal Medicaid funds from institutions to community and family living facilities over an extended period of time. Let us briefly summarize why our Association supports this important legislation:

*S.2053 corrects the current federal financial bias in favor of costly, restrictive, and ineffective institutionalization for people with severe disabilities.

*The current ICF/MR program lacks accountability; conditions at Medicaid funded institutions remain grossly inadequate.

*S.2053 supports the direction of federal policy as articulated over the past two decades.

*S.2053 is consistent with the state of the art in professional services and programs for people with severe disabilities.

*S.2053 is supported by the preponderance of research evidence on institutions and community settings.

*S.2053 is supported by studies concluding that costs for comparable services in the community are, on the average, less expensive than services in institutions.

*S.2053 would prevent the placement of persons with severe disabilities in inappropriate and ineffective settings.

*S.2053 contains safeguards on the rights and interests of people with severe handicaps and their families.

We devote our testimony to each of these points in favor of S. 2053.

THE CURRENT FEDERAL BIAS

Medicaid, specifically the ICF/MR program, is today perhaps the single most formidible obstacle to community living for people with severe disabilities nationally. By making federal funds readily available for institutionalization and requiring states to spend scarce resources for institutional construction or renovation, the Medicaid program has perpetuated institutions for people with mental retardation and other disabilities.

Under the Intermediate Care Facilities (ICF) program, the federal government provides a strong incentive for states to maintain people with severe handicaps in institutions for the mentally retarded and developmentally disabled, nursing homes, and similar facilities. Through this program, the federal government pays 50% to 78% of the costs of medical and rehabilitation services provided in "intermediate care facilities," including "intermediate care facilities for the mentally retarded (ICF/MR)." In 1978 alone, payments under the ICF/MR program totalled $1,337,325,086. Today, payments total between $3 and $4 billion per year.

As of June, 1981, the populations of public institutions for the mentally retarded totalled 128,472 (Scheerenberger, 1982). In 1980, an additional 69,024 mentally retarded persons remained in nursing homes (Lakin, et al., 1982). Thousands of others were placed in other forms of institutions, including mental hospitals and private institutions.

The federal ICF program subsidizes the costs of institutionalization for the vast majority of people with severe disabilities currently residing in public institutions and nursing homes. Scheerenberger (1982) reports that in a survey of 189 public institutions for the mentally retarded 94% were at least partially funded by Medicaid under the ICF program.

The ICF program also encourages states to invest capital funds in institutional construction and renovation. Under the ICF/MR program, states have undertaken major capital construction projects in order to insure the continued receipt of federal Medicaid monies. According to one national survey, in the fiscal years 1977-80, 49 states and the District of Columbia included in their budgets appropriations or requests for capital investment in institutions at a cost of $821,456,000 (National Association of State Mental Retardation Program Directors, 1980). Significant capital investment in institutions continues today. For example, New York and Massachusetts recently announced plans to allocate massive capital funding for institutions for the mentally retarded and developmentally disabled.

While some states have used Medicaid funds to develop community services, the vast majority of funds continue to be spent for public institutions. Further, in many instances, states have used these funds for private institutions, rather than small family-scale settings (Taylor, et al., 1981).

S.2053 replaces federal financial incentives to institutionalize people with severe handicaps with incentives to serve them in their own homes and communities.

INSTITUTIONAL CONDITIONS

Institutional conditions have improved over the past decade, though not as much as some commentators claim. With decreased populations, institutions are no longer so overcrowded and understaffed as they once were. Yet institutions continue to deprive their residents of programming, meaningful activities, and human dignity and respect.

Recent studies of Medicdaid-funded institutions indicate that the conditions that have plagued institutions traditionally persist to this day to some extent. In 1981, the Center on Human Policy issued a national report on the impact of the federal Medicaid ICF/MR program (Taylor, et al., 1981). Based on a review of federally-mandated surveys at 44 ICF/MR-certified institutions in 23 states, the report concluded that serious violations of the standards existed at all of the institutions. The surveys reviewed in this report documented a lack of programming and professsional services, unsanitary conditions, a lack of privacy, and other shocking conditions at these federally subsidized institutions. Examples of violations listed in the ICF/MR surveys included:

> . . .Sixty-four out of sixty-seven activity schedules reviewed and personal observation

in the living units indicates that residents do not participate in activities as scheduled, the schedules also showed more than three hours duration of unscheduled activity. . .

. . .Residents who were incontinent were not bathed or cleansed immediately afte voiding or soiling as observed by surveyors in Unit E and in the dining room in Holly Building. It was reported that residents were brought to the support services with wet or soiled clothing. . .

. . .Thirty of thirty activity schedules reviewed did not allow for individual activities with appropriate materials as individual needs had not been defined by the program team. . .

. . .Food was taken from one resident's mouth and placed back on another resident's tray during meal time. . .

. . .A resident who needed to be dressed was taken to a public area where there was four members of the opposite sex and undressed without any regard for the resident's dignity, and redressed. One female resident was wearing a turkish towel for a diaper. . .

. . .Fixtures, furnishings, and floors were found to be excessively soiled and some areas were objectionably odorous. The facility is also in need of more effective pest control as evidenced by a cockroach infestation in many buildings. . .

. . .Many areas do not have furniture other than beds for residents. In some cases, storage of clothes is in open bins. . .

. . .Common use of hairbrushes between residents is practiced. . .

. . .No individuial privacy provided between commodes in toileting areas. . .

. . .Seclusion was used as punishment. Only 17 of 65 residents, subject to this seclusion, were functioning with an existing behavioral plan. . .

In an indepth analysis of ICF/MF survey reports conducted by state inspectors at Mansfield Training School in Connecticut, Taylor (1982) found widespread noncompliance with federally mandated ICF/MR standards. Taylor reported that violations of ICF/MR standards actually increased over a four year period from 1978 to 1981, despite the institution's repeated assurances that violations would be corrected within a six-month time frame.

The inability of large-scale outmoded facilities to meet minimum programming standards, even with massive federal funding, is widely acknowledged by those who operate the facilities. At Mansfield, for example, the Superintendent proposed for 1984 to spend $38,000 (including federal funds) per year. Even that amount he acknowledged in his budget narrative "does not reflect the needs of our clientele for consistent basic care, protection from harm and minimally active treatment in accordance with. . .regulations governing the operation of Intermediate Care Facilities for the mentally retarded (Title XIX)."

The failure of Medicaid-funded institutions to provide a minimal level of programming or even a decent level of custodial care has been documented by other researchers as well. In 1979, Burton Blatt (Blatt, Ozolins, and McNally, 1979) published a ten-year follow-up study of his now famous photographic essay, Christmas in Purgatory (Blatt and Kaplan, 1966). Blatt found that despite a massive infusion of public fuinds institutions for the mentally retarded remain grossly substandard. In the conlusion of this follow-up study, Blatt and his colleagues make an eloquent plea for the closing of all institutions for the mentally retarded (Blatt, Ozolins, and McNally, 1979: 143):

> We must evacuate the institutions for the mentally retarded. There is no time any more for task forces and new evaluation teams. The time is long since past for such nonsense. Joint accreditation commissions do no good. We need to empty the institutions. The quicker we accomplish that goal the quicker we will be able to repair the damage done to generations of innocent inmates. The quicker we get about converting our ideologies and resources to a community model, the quicker we will learn how to forget what we perpetuated in the name of humanity.

Repp and Barton (1980) conducted an observational study of certified and noncertified units at a single institution. They concluded that there was little programming or even staff-to-resident interaction in either certified or noncertified units during normal programming hours. According to Repp and Barton, institutional units can be certified when they are not providing habilitation.

Institutional expenditures have soared since the inception of the Medicaid ICF/MR program. According to the former Commissioner of Mental Retardation and Developmental Disabilities in New York State, the average cost of institutionalization statewide stood at $53,200 per person per year in 1981. The federal government paid for half of these costs. Yet conditions at many institutions remain shocking. Programs are implemented haphazardly if at all. Institutional residents lack a decent quality of life.

TASH believes that the orderly and graduated phase-out of federal aid to institutional facilities, contemplated by S.2053, is necessary to extricate the federal government from long-term support for high-cost, custodial care.

FEDERAL POLICY

On February 5, 1983, following the findings of his President's Panel on Mental Retardation, President John Kennedy delivered a Special Message to the Congress calling its attention to the "antiquiated, vastly overcrowded, chain of custodial state institutions." 1963Public Papers of the Presidents 126, 128; 109 Cong. Rec. 1837, 1838 (1963). As to the future, the President's 1963 Message said:

> "(S)ervices to the mentally retarded must be community based...We must move from the outmoded use of distant custodial institutions to the concept of community-centered agencies. Id. at 128, 134; 109 Cong. Rec. at 1838, 1841.

The Special Message called upon the Congress to legislate:

> To retain in and return to the community...the mentally retarded, and there to restore and revitalize their lives through better health programs and strengthened educational and rehabilitation services." Id. at 137; 109 Cong. Rec. at 1842.

Congress responded by authorizing funds for comprehensive retardation plans (The Maternal and Child Health and Mental Retardation Planning Amendments of 1963, P.L. 88-156) and by enacting a new federal-state grant-in-aid program to fund community-based alternatives (The Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, P.L. 88-164).

In 1967, Congress expanded federal funding authority to include grants to the states for staffing and start-up expenses of community facilities ((The Mental Retardation Amendments of 1967, P.L. 90-170, §4, 81 Stat. 528).

In 1970, Congress replaced these authorities with the Developmental Disabilities Services and Facilities Construction Amendments, a broad, new federal-state grant-in-aid program intended (1) to provide funds to the states for "gap-filling" community services, because other statutes, for example, the Social Security Act and the Rehabilitation Act, by now provided the largest portion of federal funds to state retardation services; and (2) to focus the state's use of these other federal funding authorities upon supplying communit alternatives to institutionalization by requiring certain state planning mechanisms. See P.L.91-517, 84 Stat. 1316-21; §101(b).

In the early 1970's, Congress enacted a set of laws intended to enable severely handicapped children and adults to live, learn and grow with their families and friends in the community. Section 504 of the Rehabilitation Act of1973, P.L. 94-142, the Education for All Handicapped Children Act of 1975, and the Developmentally Disabled Assistance and Bill of Rights Act of 1975 were all a piece of the Congressional charter to reverse patterns of segregation and institutionalization of people with disabilities and return them to their rightful place in society.

In the Developmentally Disabled Assistance and Bill of Rights Act of 1975 the Congress addressed residential programs for the severely retarded. Congress embraced the standard that state residential programs "should be designed to maximize the developmental potential" of every severely retarded person and that this design could best be accomplished in small-scale (i.e., family-styled), community-based residences (i.e., in the language of the statute, "in the setting that is least restrictive of ...personal liberty"). Through the Hearings on the D.D. Act, just as in the recent S.2053 Hearings before this Committee, at no point is there identified or described, as a matter of act or theoretically, any large public institution designed to maximize developmental potential. The Senate Committee instead concluded:

> It must be recognized that the vast majority of developmentally disabled persons and the vast majority of persons now institutionalized should not be in these institutions at all. Efforts to assure proper treatment, education, and habilitation services in large institutions should not deflect attention from the fact that most of these institutions themselves are anachronisms, and that rapid steps should be taken to phase them out. Many of these institutions by their very nature, their size, their isolation, their impersonality, are unsuitable for treatment, education, and habilitation programs." S. Rep. 94-160 at 32-33 (emphais supplied).

The funding approach in S.2053 is based upon the long-standing recognition by Congress of these facts about institutions.

A significant step in moving the Federal government's policy on long-term care to include support for community alternatives to institutions was taken with the Medicaid Amendments in the Omnibus Budget Reconciliation Act of 1981. Section 2176 adds a new section, 1915(c) to Title XIX of the Social Security Act authorizing the Secretary of the Department of Health and Human Services to waive existing statutory limitations that previously prevented states from paying for home and community-based services under their State Medicaid Plan. Such waivers allow the state under its Medicaid plan to cover home care and other services for individuals who, without such services, would require institutional care in a Title XIX certified facility. Before enactment of this legislation, practically no federal support was available for long-term supportive services in community settings, even though Medicaid provided full or partial coverage for such services within nursing home and institutional settings. The Home and Community Based Services Amendment to the Medicaid plan recognized that the existing funding pattern has served as an incentive for the development of institutional services and a disincentive for the development of alternative service delivery models.

Thirty-one states have elected to provide community services under the waiver programs. Those states have demonstrated their desire to move away from institutional programs to community services. Wisconsin's waiver proposal provides a good statement of the rationale to redirect Medicaid funding from institutions to the community.

> Wisconsin has chosen to participate in the waiver program in the belief that many of the individuals who are currently residing in the State Centers for the Developmentally Disabled can benefit from services provided in their home communities. For many individuals with disabilities, community-based services offer substantial advantages. In particular, it is easier to become an active member of the community and enjoy consistent contact with friends and family members. The small, integrated nature of many community programs can provide greater opportunities for participants to be viewed as individuals and have services designated to meet their individual needs.

> The diversity of most communities and the many environments and activities available in those communities can provide an increased number of learning opportunities. Community-based programs also have the advantage of allowing the citizens of a community to gain experience with the services needed by individuals with disabilities and see those individuals living, working, and recreating in 'normal' community environments. Such experiences advance the understanding of individual differences and facilitate the acceptance of individuals with disabilities as members of the community.

S.2053 provides the next logical incremental step in the transition of federal support for residential services from one of a segregated, institutional model to a range of community and family service options.

S.2053 aligns federal financial assistance with federal policy pronouncements on the disabled. Nothing in the proposed legislation requires states to close institutions, even though this may be desirable. S. 2053 simply sets conditions on the receipt of federal Medicaid funds for services for people with severe handicaps.

STATE OF THE ART

Tremendous strides have been made in services for people with severe handicaps over the past decade. Model community and family living facilities for people with the most severe disabilities may be found throughout the nation. The Eastern Nebraska Community Office of Retardation (ENCOR) and the Macomb-Oakland Regional Center in Michigan are two notable community service systems that serve a large number of people with severe handicaps (including people with severe and profound mental retardation, multiple disabilities, medical involvements, and behavior problems) in family-scale community settings. For every individual living in an institution today, there is another individual with the same level of disability thriving in a community setting somewhere in our country.

The primary barriers to community living for persons with severe disabilities are not technological or professional. The technology exists today to serve all people in family-scale community settings. Rather, the barriers are administrative and economic in nature. They reflect the lack of clear incentives to maintain people with disabilities in their home communities.

When Congress enacted P.L. 94-142, the Education for All Handicapped Children Act, some commentators disputed whether all handicapped children could benefit from a free appropriate public education. Now hardly anyone would deny that P.L. 94-142 was morally right and programmatically sound. Today some commentators question whether all people with severe disabilities should live in normal homes and communities.

THE RESEARCH EVIDENCE

Social science research can seldom, if ever, resolve major public policy debates and dilemmas. While sound research should inform policy decisions, the research evidence alone is never conclusive. This is true for several reasons: researchers seldom agree on the key variables to study; no study follows a perfect research design; some of the most important areas of life are the most difficult to measure objectively (for example, quality of life); all researchers bring their own values, biases, and assumptions into their research. It should not be surprising, therefore, that researchers will disagree on the evidence supporting S.2053. Indeed, some may even argue that more research is necessary before supporting such a major piece of legislation.

The issues of institution versus community setting and large versus small facilities have been the subject of a large number of studies. For the reasons stated above, these studies are not all consistent. Yet a preponderance of the research evidence strongly supports the basic provisions of S.2053. Here is a brief summary of some of the research that supports the policy direction contained in S.2053:

*In a study of resident management practices in England, King, Raynes, and Tizard (1971) found that practices were more resident-oriented in smaller group homes than in either large hospitals or medium size "voluntary homes."

*In a replication of the King, et al. study in Scandanavia and the United States, McCormick, Balla, and Zigler (1975) confirmed that care practices are more resident-oriented and less regimented in community homes than in large institutions or regional centers.

*A host of sociological studies of mental hospitals and institutions for the mentally retarded in England and the United States have concluded that institutions foster dehumanization and depersonalization: Goffman (1961), Morris (1969), Biklen (1977), Taylor (1977), Perrucci (1974).

*In an English study, Tizard (1969) reported that "severely subnormal" children transferred to family-type homes made significantly greater advances in verbal and social development than a matched group who remained in a public hospital.

*A national survey of community residential facilities by O'Connor (1976) found that smaller settings were more normalized than larger ones.

*Another national study of institutions and community residential facilities by Rotegard, Bruininks, and Hill (1981) in 1978-79 reported that community residential facilities with fewer than 15 residents were much more home-like than either larger private facilities or public institutions.

*Hull and Thompson (1981) found that size was an important factor in the degree of normalization of residential institutions.

*Thompson and Carey (1980) found significant increases in intellectual functioning and adaptive behavior among residents transferred from an institution to a normalized community home.

*Eyman, Demaine, and Lei (1979) reported a significant relationship between normalization of community residential facilities and gains in residents' adaptive behavior.

*Separate studies by Knight, Zimring, Weitzer and Wheeler (1977) and MacEachron (1983) found that normalization of living units within institutions resulted in positive gains in residents' functioning.

*Rotegard, Bruininks, and HIll (1981) reported in a study of 156 private facilities and 75 public institutions that small community settings containing eight or fewer residents encouraged more resident activity and autonomy than larger private facilities or public institutions.

*In a review of the research on the relationship between residential size and the quality of services, Baroff (1980) identified seven studies that demonstrated advantages of small settings, while one study showed no difference in facilities of differing sizes.

*In an indepth study of three institutions for the mentally retarded, Bogdan, Taylor, deGranpre, and Haynes (1974) found that direct care staff members at institutions subvert innovative programs designed by professionals and administrators.

*In an observation study of licensed and unlicensed units at one institution, Repp and Barton (1980) found a lack of programming and habilitation efforts during normal programming hours.

*Conroy, Efthimiou, and Lemanowicz (1982) reported significant gains in adaptive behavior among a group of 70 individuals placed in small community settings as compared to a matched group who remained at the institution.

As noted previously, the research evidence is seldom perfectly consistent. One study which yields a different impression than the body of research listed above is cited repeatedly to justify large facilities. This study, published by Landesman-Dwyer, Sackett, and Kleinman (1980), seems to indicate there is not much difference between large and small residential facilities. However, since this study focused solely on community residences (ranging in size from six to twenty) and included a study sample that is not representative of persons currently residing in institutions, its relevance to S.2053 is dubious at best.

The Landesman-Dwyer, et al. study has been subject to misinterpretation and is characterized by methodological and conceptual weaknesses. For this reason, we analyze this study in depth in the Appendix of this statement. As our analysis indicates, this study fails to provide a sound basis for opposition to S.2053.

In concluding this section on the research on institutions and community living, it is essential to point out that not one shred of research supports the policy of institutionalization. Historically, our society has institutionalized hundreds of thousands of individuals with mental retardation, developmental disabilities, and physical impairments in the absence of scientific research. Indeed, myths and unfounded stereotypes have been the major force behind institutionalization. Even if the research evidence on the benefits of community living were less clear, it would be impossible to justify denying severely disabled individuals the right to full participation in community and family life.

COMPARATIVE COSTS OF SMALL-SCALE COMMUNITY PROGRAMS

The Senate has kept itself informed as to the conditions in large-scale institutions for the mentally retarded. Most recently, Hearings before the Senate Subcommittee on the Handicapped revealed continuing violations of basic human rights in institutions in Maryland, Connecticut and Oklahoma. However, up to now Congress has not focused on the cost of federal funding of such institutions. The cost of institutional care and comparable costs for community care should be carefully considered by the Congress in determining whether to continue federal funding for institutions into the long-term indefinite future. Early cost studies have not been helplful, because a range of community programs for severely handicapped persons have not been available, and studies often compared "apples and oranges". More recently studies have been completed reaching the conclusion that cost in the community for comparable servaices to similarly disabled persons is on the average less expensive in small scale community settings. In a carefully controlled cost-effectiveness study conducted by the Temple University Developmental Disabilities Center for the U.S. Department of Health and Human Services as part of the five-year longitudinal study of the deinstitutionalization of Pennhurst, an institution the State of Pennsylvania plans to phase out, the Temple researchers reached the following conclusions:

-- Clients placed in CLA's increased in adaptive behavior, while clients remaining at the institution did not;

-- Clients placed in CLA's were receiving greater total amounts of direct, structured, developmentally oriented services than their matched peers at the institution;

-- The public dollar amount expended for clients in the CLAs was less than that in the institution (institutional mean, \$47,000/year, median, \$47,000; CLA mean \$42,000, median \$36,000);

-- The state share of the public cost was far greater for the clients in CLAs (89%) as opposed to clients at the institution (45%).

The Temple researchers attributed the imbalance in state-federal funding share for community services to the fact that the Federal government, under the ICF/MR program, paid over half of the total institutional costs, while CLAs were not part of the ICF/MR program. S.2053 is designed to correct this imbalance and relieve the burden on states to fund community programs without federal assistance.

PREVENTION OF INAPPROPRIATE PLACEMENTS

S.2053 does not merely require the closing of institutions, but rather, encourages the planned phase-out of institutions and the transfer of financial resources necessary to ensure appropriate and successful community placements.

Over the past decade and one-half, thousands of persons with disabilities have been placed in high quality appropriate settings in the community. Yet deinstitutionalization has proceeded amid charges of "transinstitutionalization" and "dumping" (Blatt, Bogdan, Biklen and Taylor, 1977). That is to say, in some locations, deinstitutionalization has meant nothing more than the release of individuals from public institutions. Many persons have been transferred from large institutions to small ones and from custodial care facilities to non-care ones.

The populations of public institutions for the mentally retarded and developmentally disabled have declined at a steady pace since the late 1960's. However, many individuals have simply been moved to other forms of institutions. Lakin, Bruininks, Doth, Hill, and Hauber (1982) report that as of 1980, 69,024 mentally retarded people resided in nursing homes. Scheerenberger (1982) reports that over 30% (approximately 3,000 individuals) of the mentally retarded persons who were placed out of public institutions in the fiscal year 1980-81 ended up in other forms of institutions, including nursing homes, mental hospitals, and other facilities for the mentally retarded. In addition, many of what are termed "community facilities" are, in fact, relatively large, segregated institutions.

While "dumping" has not occurred in the field of developmental disabilities to the same extent as the field of mental health, there are also reports that many developmentally disabled individuals have been moved from public institutions to substandard facilities and boarding homes in the community (General Accounting Office, 1977). One recently published study by Bercovici (1983) found that many mentally retarded persons have been placed in substandard community facilities in which they are just as isolated and segregated as they were when they lived in institutions.

The passage of S.2053 would call a halt to widespread "transinstitutionalization" and "dumping". The proposed legislation contains numerous provisions to assure that the phase-out of institutions is conducted in a planned and coordinated fashion:

*The ten-to-fifteen year time period given institutions to reduce their populations to zero, which will provide states with sufficient time to engage in careful planning of services;

*The requirement that institutions develop written phase-out plans and submit progress reports, including information on individuals transferred to community facilities, every six months;

*The expansion of services reimbursable through Medicaid that will enable the diverse needs of severely disabled individuals to be met in the community; notably, comprehensive services for independent living and vocational services;

*The requirements for independent monitoring of services, the provision of case management services, and the development of a community services plan for each severely disabled individual residing in an institution;

*The requirements in regard to the location of community and family living facilities in residential neighborhoods.

While some professionals and parents have expressed fears that S.2053 might result in "dumping" of severely disabled individuals into the community, the proposed legislation represents a federal mandate to halt the placement of individuals in inappropriate or substandard facilities. S.2053 might properly be called an "anti-dumping" act.

SAFEGUARDS

S.2053 contains numerous safeguards on the rights of individuals and their parents or guardians. The proposed legislation requires an individual plan of assistance for each severely disabled individual and provides for the central involvement of parents and guardians in the provisions of services.

S.2053 establishes essential due process procedures, including provisions for an impartial hearing and private enforcement, which are currently lacking in Medicaid programs. Under the ICF and ICF/MR programs, individuals and their guardians are deprived of mechanisms through which to challenge decisions regarding proposed services and placements. In fact, the ICF and ICF/MR programs enable a facilitiy to continue to receive federal financial assistance even when placement at the facility is determined to be inappropriate for an individual.

S.2053 has generated opposition from some parents of severely disabled individuals currently residing a institutions. Our Association sympathizes with those parents who, often on the advice of professionals in another era, made a painful decision to institutionalize their children and strongly supports their rights to assure that their children receive appropriate supervision and services in the community. Often parents' concerns and fears about community living stem from the negative deinstitutionalization experiences described in the preceding section. However, we cannot agree that some individuals should be cut off from community participation simply because of their disabilities. Indeed, most parents of formerly institutionalized individuals express satisfaction with community placement over time, despite initial opposition.

Parents and guardians should have opportunities to participate in the development of individual plans and should have available mechanisms to challenge inappropriate placement and services decisions. They should have the right to assure that their children receive the community supports and services their children require. S.2053 provides these things.

CONCLUSION

The Association for Persons with Severe Handicaps joins those organizations and individuals who have given their support to S.2053. The time to return people with severe disabilities to their rightful place in the community has long since passed. Like Section 504 and P.L. 94-142, S.2053 represents a mandate to end the exclusion of people with disabilities from the mainstream of American life. Federal funds must be used only to support community participation and not isolation and segregation.

We want to offer once more our consultation and assistance to the Senate Committee on Finance in its continuing deliberations on S.2053. We stand ready to assist the Committee in strengthening this extremely sound piece of federal legislation.

In closing, our Association expresses its appreciation to the U.S. Senate Committee on Finance for its efforts on behalf of our nation's citizens with severe disabilities.

AAP ASSOCIATION for the ADVANCEMENT of PSYCHOLOGY

March 16, 1984

Senator Dave Durenberger
Chairman, Health Subcommittee
Senate Finance Committee
United States Senate
Washington, DC 20510

Dear Mr. Chairman:

On behalf of the Association for the Advancement of Psychology and the American Psychological Association (APA/AAP), representing over 70,000 psychologists nationwide, we would like to thank you for this opportunity to submit for the record our comments and concerns regarding S.2053, the Community and Family Living Amendments of 1983. We also wish to commend the Committee, and its Members, for its interest in the needs of the mentally retarded (MR) and developmentally disabled (DD) persons in this country.

S.2053 would provide mentally retarded and developmentally disabled persons with greater access to community-based treatment. In so doing, the legislation is responding to the importance of offering these persons effective alternatives to institutional-based care; a finding that is well-documented in the psychological literature and substantiated by the trend of the past decade away from institutional care for all but the most severely mentally retarded or developmentally disabled individual.

In its present form, S.2053 would amend Title XIX (Medicaid) of the Social Security Act so as to effect a shift in Medicaid funding from large institutional (16-2,000 bed) providers of intermediate care to small community-based (fewer than 10 bed) providers. A change that is needed to correct the institutional bias that set in after 1971, when Congress amended Title XIX to permit reimbursement for services provided in intermediate care facilities (ICFs), and the States amended their own Medicaid plans to include intermediate care facilities for the mentally retarded (ICFs/MR). However, in its present form, S.2053 accomplishes that end to the detriment of institutional-based care: it creates a "community-bias" whereby institutional care is no longer a financially viable option.

At present, there are only three forms of Medicaid-certified providers to serve the mentally retarded and developmentally disabled population: intermediate care facilities, intermediate care facilities for the mentally retarded, and skilled nursing facilities (SNFs).

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The majority of MR/DD persons receiving institutional care do so in the large ICFs/MR setting. This is because of the high level of professional care that can be offered at such facilities and the financial constraints that limit a family's range of options.

A primary concern with the implementation of this deinstitutionalization program is that quality of care must not be sacrificed as a result of the change. Many large institutions are capable of providing a wide range of services along with sophisticated professional care. Proper treatment of the mentally retarded and developmentally disabled requires that they have access to a full range of health care practitioners, appropriate therapeutic and rehabilitation programs, and high quality nutritional and life/safety standards. Anything less would be to shirk the responsiblility that is ours. The present Medicare and Medicaid statutes and regulations discriminate against the provision of the full range of professional services required by those in need of help for mental illness, developmental disabilities and mental retardation. For instance, Sec. 1833(c) of the Social Security Act which limits Medicare payment for mental and emotional illnesses to $250.00 with a $250.00 co-payment and restricts access to mental health professionals, has not been improved since Medicare's inception in 1967. The opportunity exists for Congress to address these issues in the present legislation as part of a partial deinstitutionalization program. Such programs and facilities must be in place before larger institutions could be phased out.

Congress took the first step toward deinstitutionalization when it included Section 2176 in the Omnibus Reconciliation Act of 1981 (ORA). In essence, that section granted the Secretary of the Department of Health and Human Services the authority to waive certain Medicaid requirements to permit States the flexibility of establishing home and community-based long-term care delivery systems for Medicaid-eligible individuals who were at risk of institutionalization. This represented a significant advancement in providing a full range of care to the mentally retarded or developmentally disabled person who requires 24-hour care. And it continues to offer the greatest assurance that a full range of options will be retained in the future.

The present legislation, however, would phase out all of the large Medicaid-funded ICFs over the next 10 years. The only exceptions to that phaseout would be the exemption granted to those facilities with fewer than 15 residents at the time of the bill's enactment, and the 5 year extension for those facilities that were opened after January 1, 1979 and maintain 16-75 residents. Yet, the net effect of this action would be to eliminate one inequity by creating another: the availability of community-based care needs to be expanded, and it is equally important that institutional-based care continues to be provided. This is especially true for the profoundly retarded individual who simply cannot obtain a comparable level of professional care in the smaller setting; for them, the consequences of deinstitutionalization are literally a matter of life and death. Similarly, there are those for whom deinstitutionalization would result in homelessness.

There are significant difficulties in obtaining community and zoning approval for the small group facilities that are envisioned by this legislation. Experience has shown that citizens favor deinstitutionalization from large facilities but fear loss of property values and "neighborhood peace" if a MR/DD group home were to be located in residential areas. In spite of this community fear, however, these small group homes have not proven to be disruptive. But, the committee needs to consider the political impediments to rapid development of community resources as opposed to the good intentions of the public policy that is proposes.

Beyond the social concerns of this legislation, attention must also be focused on its economic aspects. In its present form, the bill would provide a 5 percent increase in the Federal Medicaid matching rate for 5 years for each deinstitutionalized individual. Yet, there is insufficient data to indicate that this amount could cover the transition costs involved in dismantling one system and establishing another. For if there is a lesson to be learned from history, it is that the beneficiaries of this legislation will be the ones to suffer from any miscalculation of judgment or cost excess. And their suffering is likely to carry with it some very real consequences; namely, a reduction in the quality of care being provided and the elimination of vital services.

Furthermore, the economic impact of this legislation would adversely affect those who are employed by the institutions. The employment assurances contained in the bill's present form do not provide ample safeguards against the unemployment and displacement of workers. And it is crucial to the success of this program that these highly trained professionals are not lost from the workforce.

In sum, our concerns with this legislation as it is currently drafted are: that the option of institutional care be retained; that there are adequate assurances that a high level of professional care can be maintained in a small community setting; and that the closing of the larger institutions will not produce an economic hardship on its employees. As an alternative to the problems that this bill would create, we respectfully suggest that the Committee consider utilizing the existing Section 2176 Medicaid waiver provisions as a more efficacious means of accomplishing a worthy end.

We appreciate the Committee's willingness to accept our comments and entertain our proposals.

Sincerely,

Michael S. Pallak, Ph.D.
Executive Officer
American Psychological Association

Clarence J. Martin
Executive Director and General Counsel
Association for the Advancement
of Psychology

ASSOCIATION FOR RETARDED CITIZENS - CALIFORNIA
1414 "K" Street, Suite 300
Sacramento, CA. 95814 . (916) 441-3322

TESTIMONY PREPARED FOR SUBMISSION TO THE UNITED STATES SENATE COMMITTEE ON FINANCE, SUBCOMMITTEE ON HEALTH, PERTAINING TO S. 2053,"COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983"

FEB. 27, 1984

I am Owen Mock, president of the Association for Retarded Citizens-California, an organization consisting of fifty-two (52) local units representing all regions of the state. Our principal reason for existence is that of working to bring about quality programs and services for the more than 660,000 mentally retarded residents in California. We applaud the basic intent of S. 2053, that of making available the federal funds required to guarantee adequate quality community residential services. Each mentally retarded individual must be assured the right to live in or near his or her home community and we enthusiastically support that provision of the bill.

We also endorse other provisions of the bill which require: that the quality of services be reviewed and monitored by an independent entity; that case management services be provided; that protections to preserve employee rights and benefits be established; and that all staff receive adequate and continuing training. We believe that quality health care and all other services are best available in those same communities in which we choose to live. In short, we share the same goals as the sponsors of S. 2053, the right for each individual to be a part of the community and share those rights and privileges which each of us considers inviolable.

We must part with the sponsors of S. 2053 in certain sections of the bill which deal with process. The bill appears to assume that all of the fifty states are starting from approximately the same point, and that for all practical purposes each state can begin and end a process at the same time, and with equal and positive results. We maintain that the several states are vastly different, that they are not all at the same point in a transition to adequate quality community living arrangements. Among our basic concerns are the following:

1. It is impossible for each state to accomplish a total change to community residences of ten or less in a period of ten years. California currently has 7,000 individuals residing in its state-operated congregate care institutions and at least another 7,500 who would require the same type of community facilities over the ten-year time frame. Small homelike facilities, housing ten or fewer, would require a construction schedule of approximately 1,400 units per year. The availability of adequate state funds to meet that schedule cannot be assured.

   There is also the fact that use permits, zoning restrictions and restrictive covenants must all be dealt with before building can even begin. It is a simple fact that laws are not always changed easily and if an impasse in that regard should occur, California would lose its current federal funding and the mentally retarded citizens of this state would bear the brunt of a political misapplication of justice.

2. Whether or not a maximum of 9 or 10 residents per facility is the most appropriate size remains to be proven by history. In the meantime, we cannot accept someone's arbitrary judgment that such is the case. Because of the diverse needs of the mentally retarded population, it may be possible that facility size, in some cases, should be in the 20 to 25 range. There is no conclusive evidence that small is good and there must be opportunity for flexibility in facility size. The havoc caused by such restrictive and rigid size requirements would probably be of very substantial proportions.

3. We are deeply concerned with the lack of attention to standards and a monitoring process. Section 1918(i)(1)(L) calls for each facility being accredited

by the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons (or another appropriate national accrediting body) or is licensed or certified by an appropriate state agency. Allowing a state licensing procedure to substitute for accreditation by ACMR-DD is tantamount to the continuation of an unacceptable process now used in California. Permitting each state to accredit its own facilities through a license is totally unacceptable. A monitoring plan in the bill is chiefly noticeable by its absence.

I must also note that I do not believe this bill should be merchandised as a less expensive system of residential services. State institutions have a reputation for being more expensive largely because of the salary disparity. While state employees have finally achieved some semblance of adequate pay for their work, community facilities often pay at or near minimum wages. If we expect to develop a quality community residential system, we must pay appropriate wages. Quality staff can only be recruited and retained if fairly compensated. A plan which allows for the transition of congregate care employees into community facilities demands higher wages. Whatever real cost difference there may be between community and institutional facilities will most likely disappear if quality residences are developed. No individual legislator should support S. 2053 because of its cheapness.

We do believe, as already stated, that each individual has a right to live in the community. We cannot, however, accept the rigidity of S. 2053's ten-year transition period nor the arbitrary size imposed upon the community facility. The bill must be revised in these and other areas I have touched upon before it can be supported by ARC-California. In its present form the bill's enactment could very well destroy one system without constructing a better one in its place. Surely, we cannot take that chance. Give us a bill with flexibility that truly recognizes the individuality of each state and the mentally retarded citizens who dwell therein.

SUMMARY OF TESTIMONY PREPARED FOR SUBMISSION BEFORE THE UNITED STATES SENATE COMMITTEE ON FINANCE, SUBCOMMITTEE ON HEALTH, PERTAINING TO S. 2053, "COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983"

ARC-California **agrees** with the following provisions of S. 2053:

A. The diversion of federal funds for the support of community living arrangements;
B. That the quality of services be reviewed and monitored by an independent entity;
C. That case management service be provided;
D. That protections to preserve employee rights and benefits be established; and
E. That all staff receive adequate and continuing training.

Major issues with which we **disagree** are as follows:

A. The bill appears to assume that all of the 50 states are starting from approximately the same point, that for all practical purposes they can begin and end a process at the same time and with equal and positive results. We maintain that the several states are vastly different and that the 10-year transition phase is highly unrealistic. Start-up costs and zoning problems are major obstacles.

B. The arbitrary size of 9 to 10 residents per facility is not based upon solid evidence and greater flexibility in size is required.

C. We are deeply concerned with the lack of attention to standards and a monitoring process. Permitting each state to accredit its own facilities through a license is totally unacceptable.

D. A monitoring plan is chiefly noticeable by its absence in the bill.

In summary, the bill is not acceptable in its present form. Without major overhaul its enactment could very well destroy one system without constructing a better one in its place. We are also dismayed that supporters of the bill have introduced its purported "cheapness" as a significant reason for its passage. Quality community living arrangements are not likely to cost less than institutional programs.

2/21/84

900 South Fourth Ave.
Libertyville, Ill. 60048
Feb. 19, 1984

Mr. Roderick DeArment
Chief Counsel and Staff Director
Committee on Finance, U.S. Senate Rm. SD.219
Washington, D.C. 20510

Dear Mr. Roderick DeArment,

I am writing to you about the Senate bill 2053, "The Community and Family Living Amendments Act of 1983," introduced by Senator Chafee of Rhode Island. It would greatly limit Medicaid funding to disabled and mentally retarded people who live in a small community facility of more than 10 people. I would like this bill to be cancelled and defeated and not amended in any way. I request that this letter be entered as testimony.

Families should be free to choose the best living environment for the mentally retarded person. The size of their residence should not determine if Medicaid may be received.

It is fine if some people wish to live in a small community home of 10 or fewer residents. I feel, however, that it isn't the best atmosphere for many retarded. Many MANY thrive on the stimulation and excitement of a large home.

Beyond the personal environment and quality of life issue, there would be serious financial problems involved in placing all the mental retarded in small community homes. The uprooting of the people, introducing them to the new life-style; getting good qualified, caring personnel; and inspecting each home would be all additional problems. For these reasons I urge you to vote for the final and absolute defeat of Senate Bill # 2053.

Thank you.

Sincerely,

Judy Anderson

Dr. and Mrs. Jack Bartholmai
Route 4, Box 182
Beaver Dam, Wisconsin 53916

Senate Finance Committee
Subcommittee on Health
United States Senate
Washington, D.C. 20510

February 8, 1984

Re: Senate Bill #2053 "Community and Family Living Amendments"

Honorable Senators:

As parents of a profoundly retarded child, who is now living at Central Wisconsin Center for the Developmentally Disabled (CWC), we are concerned as to the effects of SB2053 on her life and the lives of other institutionalized retarded with medical problems. This letter is meant to give you an example of the contrast between good institutional medical care and care received in a community setting.

Our daughter, Wendi, is mentally retarded along with severe spastic tetraplegia and microcephaly. She requires 24 hour a day nursing and medical care including the administration of medications to controll muscle spasms and seizure activity.

At CWC, registered nurses are on duty 24 hours a day, medicines are dispensed by them, and medical needs are brought to their attention as soon as they are noticed by the staff. Physicians, who are employed by CWC, are called in to see our daughter and diagnose and treat her as needed without having to move Wendi from her unit. If hospitalization is needed, CWC has its own. These nurses and physicians have developed, through years of experience, special skills and expertise in the diagnosis and treatment of medical problems in the mentally retarded. They have an interest in and understanding of the retarded as human beings with feelings, fears, and needs just like anyone else. They express sadness and joy over the health status of their patients and have always kept us, as parents, well informed of our daughter's well being.

In contrast, let us tell you of some of our experiences with medical facilities outside of Central Wisconsin Center.

In 1981, our daughter was admitted to a Madison hospital for a gastrostomy (a tube placed directly into the stomach for feeding). The attitude of the physician and nursing staff towards the dignity of our daughter's life is reflected in the events that occured. Wendi's routine medications to control spasm and seizure activity were often not given on schedule or lost due to poor administration technique or failure to notice that they were vomited out soon after being given. Nurses did not respond to call buttons and trips to the nurses station by parents when Wendi was in great distress from pain or gagging. Wendi's face became swollen and skin broke down from lying in wet caustic bedding. A bladder and surgical sight infection developed due to poor hygiene care. Nurses were overheard saying, "she (Wendi) doesn't know the difference." Frequent calls to the physician in in charge were never answered, and we were unable to talk to him throughout the hospitalization. Our daughter returned to CWC with bed sores and infections all due to lack of proper care. The staff at CWC was enraged, as were we, at Wendi's condition.

These are not isolated incidents, but rather a pattern we and other parents have experienced with our retarded children in hospitals in the community setting. Medical professionals in the community are used to treating "normal" sick people and lack the expertise, interest, experience, and often proper attitudes needed in the proper and humane care of the profoundly retarded. Medical and nursing schools as well as resident programs do not deal in the treatment of the retarded or create specialists in this field. Only those medical personelle who truly care about the well-being of the retarded and work in a place such as CWC will gain the expertise required to handle their needs.

Senate Bill 2053 will, within 10 years on enactment, indiscriminantly close all institutions for the mentally retarded and thereby shut the door to medical care being obtained in a place where the staff has the aforementioned skills and interest in the retarded's well-being. SB2053 actually requires that "homes" for the retarded not be near a hospital. This bill would, therefore, put an unusual burden on local physicians and hospitals scattered about communities in the United States. As a father of a retarded child and a physician, I ask you to consider the medical implications of SB 2053. As caring parents, we ask you to investigate the effects of moving children like ours into community settings. Will the availability and quality of medical care be as good or better than presently obtain in the institutional setting? Where will the medical professionals with necessary attitudes and expertise in the care of profoundly retarded come from? Will these children survive in the community "home"?

We feel that SB2053 threatens the health and dignity of children like ours and indeed their very survival. We oppose this bill for many reasons, the greatest of these being its failure to insure the availability of health care services equal to or better than those presently received in good institutional settings.

Sincerely,
Holly Bartholmai
Jack C. Bartholmai
Jack and Holly Bartholmai

TESTIMONY TO THE SENATE FINANCE COMMITTEE
IN OPPOSITION TO SENATE BILL S-2053

Parents and Friends of Belle Chasse
State School
P. O. Box 1522
Belle Chasse, LA 70059

THE PARENTS AND FRIENDS CLUB OF BELLE CHASSE STATE SCHOOL, BELIEVING THAT ALL LIVING OPTIONS, BOTH INSTITUTIONAL AND COMMUNITY SERVICES, SHOULD REMAIN OPEN TO RETARDED CITIZENS, OPPOSE SENATE BILL S-2053, COMMUNITY AND FAMILY LIVING AMENDMENTS ACT, BECAUSE IT WILL CUT OFF ALL INSTITUTIONAL FUNDING.

The Parents and Friends Club of Belle Chasse State School is an organization composed of relatives of residents of the school, professionals and other interested friends who are dedicated to the enrichment of the lives of the retarded children and adults living at BCSS. Besides our efforts to provide special activities during the year, we have provided funds for such projects as a swimming pool, special equipment and wheelchairs, audio-visual aids and sports equipment and uniforms. We have worked closely with the administration and staff to identify areas where our assistance can be most beneficial.

Special services for the disabled in Louisiana are administered regionally, with Belle Chasse State School the center of services for a four-parish region. Under this regional management system, we have seen a commitment to develop a full-spectrum community services system coordinated by case managers. In the 1984-85 regional plan, needs were identified for residential living options including residential facilities, group homes, supervised apartments, foster care, respite care and home living with the requisite support services necessary for each. In support of this commitment for a full range of options, our group has cooperated in setting up several group homes in our community. We are trying to help increase community awareness and acceptance through our educational efforts. Many of the residents at BCSS have benefitted from these new options and are able to live more independently in the community. We feel the mechanisms are in place in the state to develop community services. We feel federal incentives will be more effective in encouraging new progress in developing programs than imposition of penalties.

We feel strongly that Senate Bill S-2053 is a threat to the rights of retarded citizens for an appropriate, INDIVIDUAL, treatment plan. To mandate a single option for services under strong budgetary and time constraints will cause unconscionable hardship as many severely handicapped individuals are deprived of the special services they require. Senator Chafee's bill is a well-meaning attempt to provide optimum care to the retarded, but is unrealistic in its insensitivity to the wide range of disabilities to be served. He disregards the need to assess the varying needs of each individual. Believe us, we want the best for our children. That "best" must be the result of a carefully thought out decision by parents or advocates and professionals who are familiar with each person's unique needs.

We are concerned that implementation of such a mandate would cause a fragmentation of services. Without a strong case management system and support services in the areas of education, training, recreation and medical assistance already in place it would be very difficult to identify and provide for the needs of persons in various programs. We do not want the special few with severe or multiple disabilities to "fall through the crack" as centralized services disappear. In the same way, persons requiring services in rural areas would be deprived because their small communities would be unable to meet their needs.

The continuing emotional debate over "BIG BAD" institutions and "SMALL GOOD" community homes is an unfair indictment of many dedicated persons providing excellent care and training to residents in large facilities. The issue is not large versus small, but is in fact our demand for excellence, no matter the size or location of a facility. Our goal is for all retarded persons to be treated with dignity and caring and helped to achieve the most they can. Strict standards and strict enforcement of these standards can help to achieve this goal, not the closing down of facilities already providing superlative care.

Lowering of costs has been cited as a fundamental benefit of S-2053. To date, none of the cost studies have proven conclusively such a claim. Group home costs for high functioning individuals, excluding all medical and educational costs, are hardly comparable to the costs of 24-hour facilities caring for predominantly severely and profoundly handicapped individuals. As parents and friends of the retarded, we would urge passage of this legislation, no matter the cost, if we felt our children would be better served. However, we ask you not to consider passage of a bill that would spend more money and would cause abandonment of needed services to our most severely handicapped persons.

There are some who claim to speak for the retarded who have endorsed this legislation. The National Association for Retarded Citizens has approved S-2053, without endorsement of its individual members or the member state bodies. The Louisiana ARC has taken a formal position in opposition to the bill which we attach. Dissension among providers of care is not new, and in fact is welcome for development of creative solutions to the problems of developmental disabilities. Listen to the endorsements of S-2053 as voices calling for expansion of services desperately needed to enable some individuals to live independent and happy lives. But please heed the voices of those who protest passage of S-2053. We do not propose institutionalization for all! We want to preserve an existing option which works for many by providing a sheltered, safe environment where an individual can thrive without the dangers and frustrations of a so-called "normal" life. Indeed the definition of normal is as varied as the number of individuals on the face of the earth.

Please, vote against Senate Bill S-2053 and preserve our right to choose a safe and appropriate environment for all retarded persons.

RESOLUTION

BE IT RESOLVED by the Louisiana Association for Retarded Citizens that:

WHEREAS, The Louisiana Association for Retarded Citizens believes that for the vast majority of persons with mental retardation a residential living option within the community is the appropriate placement; but that the Louisiana Association remains firmly committed to the development and provision of a wide range of appropriate residential living options; and

WHEREAS, The Louisiana Association does not believe that the provisions of Senate Bill 2053 which mandates the total phase-out of Title XIX funds to all facilities other than "community or family living facilities" as defined in the Act will advance the provision for a wide spectrum of residential living options in this state; and

WHEREAS, Senate Bill 2053 has the effect of eliminating the right of an individual with developmental disabilities to choose a preferred residential living option as provided by Louisiana Law:

BE IT THEREFORE RESOLVED that the Louisiana Association for Retarded Citizens opposes the passage of Senate Bill 2053.

BE IT FURTHER RESOLVED that the Louisiana Association for Retarded Citizens supports new federal legislation which would:

1. Add "home and community-based services", as that term is currently used in Section 1915 (C) (4) (B) of the Social Security Act, as an optional service which states may elect to cover under their respective medical assistance plans, submitted in accordance with the provisions of Section 1902 of the Act.

2. Amend Section 1915 (C) of the Act to specify that in order to qualify for approval of a new or renewal waiver request, on or after July 1, 1984, a state must enter into an agreement with HHS which outlines the steps it will take to assure that, no later than ten years after the initial date of approval, a full array of home and community-based services will be available, statewide, to Medicaid-eligible elderly, blind and disabled individuals capable of benefiting from such services.

3. Amend Section 1902 (A) of the Act, effective July 1, 1984, to increase the federal matching ratio for home and community-based services, delivered in accordance with an approved Section 1915(C) waiver request or as an optional service under a state's Medicaid plan, by five percentage points above the percentage a state is otherwise entitled to receive under the provisions of Section 1905(B) of the Act.

4. Explicitly authorize the states to cover pre-vocational services for eligible, non-elderly disabled persons under a home and community care waiver program and/or a state plan amendment.

5. Amend Section 1915(C) (2) (D) of the Social Security Act to limit the Secretary's authority to place certain restrictions on the manner in which average per capita expenditures are calculated for purposes of determination whether a state qualifies for a home and community care waiver and/or (B) is eligible to furnish under the proposed optional state plan amendment.

6. Amend Section 1902 of the Act to require that HHS conduct validation surveys for the purpose of determining if participating state are fulfilling the terms of their agreement with HHS, as outlined under Item 2 above.

Adopted by the Board of Directors on January 22, 1984.

STATEMENT
SUBMITTED FOR THE RECORD

ON S.2053
"COMMUNITY AND FAMILY LIVING AMENDMENTS ACT OF 1983"

BY
BEVERLY ENTERPRISES

TO THE
SUBCOMMITTEE ON HEALTH
OF THE
SENATE COMMITTEE ON FINANCE

Jack A. MacDonald
Vice President - Government Relations
1901 N. Ft. Myer Drive
Suite 302
Rosslyn, VA 22209

February 27, 1984

Introduction

Beverly Enterprises provides care for individuals with mental and physical disabilities in many settings across the United States. We presently operate facilities in eight states which are specifically dedicated to providing services to children and adults who suffer from mental retardation or psychiatric disorders. These facilities range in size from 38 to 208 residents.

S. 2053, which seeks to divert ICF-MR Title XIX funds from "large" institutions (larger than sixteen beds) to smaller residential programs, raises issues deserving far more careful analysis than apparent to date. Those issues include cost of care, numbers and types of services available in the community, quality and monitoring of services, and adequacy of safeguards for health and life safety. Based on our experience and the findings from a number of studies, we feel that a group home or "small" residential program are not the only appropriate settings for meeting the needs of the mentally retarded nor the developmentally disabled.

Background

Prior to the availability of federal funds from Title XIX, states were appropriating general State revenue funds to support intitutional services for mentally retarded persons. There was a wide range of quality in the care rendered in these facilities throughout the country. During the 1960-1970 decade, many states were involved in litigation in which the plaintiffs argued that the legal and constitutional rights of persons in these institutions were abridged.

The Intermediate Care Facility for the Mentally Retarded (ICF-MR) program was developed by the federal government during this time (early 1970's) and most states eventually participated. The government objectives behind this development were numerous. They included a desire to apply consistent standards of care to all institutions to improve the quality of care in these institutions, and to create community based programs for mentally retarded persons. The hope was that institutions would be helped by a massive infusion of federal funds to prepare people for moving to their home communities.

During the last decade these objectives were met. Quality of services rendered to persons in state schools/hospitals increased substantially and thousands of persons were transferred or discharged to both public and privately owned, community-based ICF-MR facilities. This has been possible due to the availability of ICF-MR Title XIX funds. It is important to note that there are at least four settings of care within the ICF-MR system. Those are (1) large state institutions, (300-2,000 residents), (2) private community-based facilities (generally 30-90 residents), (3) public and private 15 bed ICF-MR facilities, and (4) 8 beds or less group homes. Medicaid support for these settings vary by state according to their program.

Position on S. 2053

Beverly Enterprises is concerned as to the impact of the Community and Family Living Amendments Act, as written, on the basis that it would withdraw funding from the well-developed system of residential, habilitation, training and support services currently being provided to developmentally disabled through the ICF-MR Program. We do support the further development of community based living alternatives but not by eliminating existing programs which are providing cost effective quality services.

A discussion of our contentions regarding S. 2053 follows:

1. No one setting or service delivery model can appropriately meet the needs of all developmentally disabled persons. A major feature of the bill is that Medicaid payments would only be permitted on behalf of eligible individuals residing in a "community or family living facility". This is defined as a community based home with a capacity no greater than twice the number of persons in the average family household in the area where the facility is located (maximum of 5-6).

    a. These is no independent evidence that independent living skills can be taught only in a certain size facility or that developmentally disabled persons progress slower in larger settings, given the same individualized care.

    b. Size is not a guarantee of success. Without the provision of training, opportunities for vocational and social activities, and outside monitoring of programming, it is possible that a "small" home may be even more sterile than that of a large residential facility. Studies of the Willowbrook case, produced by the New York State Commission on quality of care for the mentally retarded: Willowbrook From the Institute to the Community, and various facilities in California have revealed that in some cases smaller environments do not function as well as larger ones.

c. Developmentally disabled persons have varying and diverse needs. In addition to suffering from mental retardation, an individual might also, for example, be deaf, blind, epileptic, and unable to speak or walk. Service requirements may vary from the need for vocational training and money management skills to the need for intensive medical care and therapy services. Larger institution ICF-MRs can offer residents a number of services: registered nurses, speech pathologists, speech clinics, and education departments with teachers trained in special education, music therapy and recreation therapy. A continuum of programs and living alternatives are necessary to meet the changing needs of an individual at any time of life. Sometimes the placement most appropriate to meet a person's needs is a larger facility where the needed professional staff and services are immediatly available.

2. The proposed care system will increase costs. It has not been substantiated that small facilities are less expensive than larger facilities. Quite the contrary is true. We have several questions regarding the cost savings to the Federal Government

as portrayed by the Congressional Budget Office's report.

a. For example, the state of Texas define three levels of care for ICF/MR; as Severely Retarded; Moderately Retarded and Mildly Retarded. Mildly Retarded has a cost to the state of $52.86 per day, per patient bed with a bed requirement of 15 or less. Moderately Retarded patient care cost is $44.54 per day and Severely Retarded patient care cost is $54.89 per day with no restrictions on the number of beds.

This clearly draws into question the argument that small facilities are less costly since the most expensive rate is paid to the smallest facility for the least disabled patient.

b. An apparent conflict in the cost data is also produced by the lack of a common definition of the various existing "institutional" and community programs. Although the study attempted to limit the definition of a residential facility for survey purposes, it did not differentiate between facilities according to types or numbers of services offered. Instead, it emphasized publicly owned versus privately owned facilities and facility size. Cost data will, of course, be affected since types and number of services, and staff needed to provide services will alter the costs.

For example:
The data regarding number of private and public facilities in each state is questionable. The figures for Texas, for example, report 73 publicly operated facilities with 4,546 MR Residents. These figures do not correlate with figures from Texas State agencies. For example, the agencies report 42 publicly operated facilities. It appears many facilities were included that should not have been.

Additionally, institutional usually refers to the large state schools and not the smaller private, community based ICF-MR facilities although both are classified as institutional and maybe funded under the Medicaid program.

Furthermore, unless covered by ICF-MR regulations, services provided in a community residential facility or group home may range from a basic room and board program, to a highly supervised support service program for the profoundly disabled individual.

c. Smaller does not necessarily equate to lower costs. Discussions with officials associated with 8 beds or less programs in Pennsylvania, New York, and Michigan have revealed costs that are two to three times the cost of ICF-MR community based care. In Michigan, the McComb-Oklahoma Development Center, which is responsible for 1,300 developmentally disabled persons, reports average costs of $70 to $130 day.

This does not include any specialized equipment, transportation or medical care. Costs in New York range from $95 to $155 per day. It was reported that Pennsylvania has picked up 45% of the cost of care for individuals in the institution; following deinstitutionalization to the community, the state's share escalated to 89%.

Studies, other than those previously cited, and some of their findings are:

- "Comparative costs of Public Residential and Community Residential Programs", (in Texas), Texas Tech University, concluded: "Based upon the data collected in this survey, the costs of providing community based residential services appear to be at least equal to if not greater than those in a public residential facility . . . . One should try not to "sell" group home care as being better than care in a public residential facility because of lower cost."

- "The Cost of Community Residential Care for Mentally Retarded Persons", Clearing house on the Handicapped, Inez Fitzgeral found that: the development of community residential facilities entails a shift of public funds, with fewer federal monies used and a greater dependence on state funding.

- Unpublished 1981 report by the Department of Health and Human Services: Long Term Care: Background and Future Direction, cites the several factors influencing per diem rates as differences between geographic regions; capital expenditures to upgrade institutions which have been factored into rates, and the level of disability of residents (which affects composition of a facility's staff and is equal to 75% of institutional costs).

- "Long Term Care: Background and Future Directions" U.S. Department of Health and Human Services reported that there is little evidence that coverage of community based and in home services reduces total public expenditures. Most of the evidence is to the contrary. This is because expanded service benefits largely go to a new (additional) service population rather than substituting for institutional care.

c. S. 2053 proposes to expand coverage to individuals with a developmental disability manifested before he attains age 50, rather than the current requirement of 22. It also would allow coverage of severely disabled children who live with their natural or adopted families and who have been ineligible because of their families' income and resources. While this is commendable, we question what consideration has been given by the Congressional Budget Office to the cost of serving this new and greatly expanded population. This is indicative of the "woodwork effect" cited in a 1981 report by HHS' Region X Office of Inspector General. The report said that although there is a great public demand for more community based services, it feared a "woodwork effect" where a large number of people not currently taking advantages of financed services, would do so if made available.

3. Quality of care and the safety of the deinstitutionalized person will be diminished due to an inadequate community support system, inconsistent standards of care/licensing requirements, and insufficient monitoring. S. 2053 would terminate, over a period of years, Medicaid funding to any facility serving over sixteen persons.

    a. Past experience has shown that deinstitutionalization, of the mentally ill, without an adequate community system of services is detrimental to these individuals' own health and safety. S. 2053 proposes a narrowly defined system of care and we are skeptical of the ability of the government to prevent the "dumping" that has and may occur as states are required to deinstitutionalize.

    b. Studies reveal that many mentally retarded persons in "community" settings received inadequate medical care and suffered more health problems than those in a setting with a treatment program and medical personnel who are willing to treat them. A study conducted by the University of Massachusetts entitled "The Status of Health Care for Deinstitutionalized Mentally Retarded People in Massachussetts: Present and Future Directions," reports that the state found: (1) current health systems are reluctantly responsive to the deinstitutionalized, (2) many of the skills needed by the physician exceed those which he customarily received during training (3) provision of medical care to the mentally retarded persons is exceedingly complex and time-consuming for the physician, (4) direct care staff and medical care staffs are usually ill-prepared or knowledgeable to deal with the mentally retarded's health problems, (5) doctors, dentists, and nurses have a problem in managing people whose appearance or behavior is different and want them segregated from other patients, and (6) 25% of the sample had difficulties in obtaining medical services.

c. Thousands of new providers, often in the form of converted private homes, would be generated by this bill. Residents would supposedly partake of a multiplicity of services offered by an assortment of providers, all operating under various standards and authorities. The homes, according to current requirements, would operate under minimal licensing and fine safety standards (depending on size and state/local codes.) We would question the value gained in the quality of life for the individuals unless the providers were monitored to protect the health and safety of the mentally retarded residents to the same level as in the other nursing facilities. This would create a new administrative burden for the state and Federal officials at a sizeable new cost.

States have been wrestling unsuccessfully for a number of years with enforcing the Keys Amendment which governs the licensing of boarding homes where many aged and disabled persons reside. A tragic thought is that S. 2053 may very well push even more disabled persons into substandards boarding homes. Problems with safety standards in these settings have received national press attention for years.

4. Sufficient incentives already exist for appropriate deinstitutionalization under the "Home and Community-Based Waiver" provisions of the Omnibus Reconciliation Act of 1981.

   a. This Act allows states to finance non-institutional long term care services through the Medicaid Program. This new waiver authority has presented the states with an excellent opportunity to experiment with alternative approaches and to determine their cost effectiveness. States have responded to this opportunity. As of July, 1983, 44 states had submitted 86 waiver applications. Most states have recognized any transfer of large numbers of persons from institutions to community must be done with considerable planning and preparation. This is to assure that appropriate services are in place to guarantee that the quality of life will, in fact, be improved.

   b. The waiver includes safeguards on program costs and sizes. The statute requires states to provide an assurance that the per capita Medicaid program costs will not increase as a result of the waiver. Also, states are not able to use the savings generated by keeping people out of institutions to provide services to "new" clients who may not have gone into an institution although they themselves would meet the criteria for receiving services.

   c. Finally, we believe states, not the federal government, should have the primary responsibility for planning a continuum of services for their aged and disabled citizens. It appears with few exceptions, that states see a need to include a varied number of institutional beds as part of that continuum.

In conclusion, we would oppose S. 2053 as currently drafted on the grounds that the system of care it proposes would in fact be detrimental to the care of the developmentally disabled.

Appropriate planning and research have not yet been done. Numerous questions, including those we have raised, need to be addressed about the practical implications of restructuring the way in which services to the developmentally disabled are provided.

The current system is not perfect but it should only be replaced with well researched and independently tested techniques for meeting the needs of the developmentally disabled. It should not be replaced by a program whose foundation is the size of the facility rather than the practical ability of the facility to provide the necessary trained staff and appropriate services in a safe environment.

We believe that yes in some instances those three qualities can be met in small facilities but there is no basis for establishing an arbitrary rule at a given bed capacity. Any limits should reflect an assessment by state and local authorities of the needs of the involved population and the resources available in the facilities to meet those needs.

We stand ready as a provider to participate in any research or studies designed to perfect the best service program for the developmentally disabled. At the same time we are willing to support the work of this Subcommittee in developing the legislation to implement such a system.

We appreciate this opportunity to present our views on the "Community and Family Living Amendments Act of 1983"; S.2053.

PHONE
ALTON Area Code 618 466 0367

"BEVERLY FARM" SCHOOL—ESTABLISHED 1897
"BEVERLY FARM" FOUNDATION—ESTABLISHED 1957

BEVERLY FARM FOUNDATION
A NON PROFIT CORPORATION
A HOME & DEVELOPMENT CENTER FOR RETARDED CHILDREN & ADULTS
6301 Humbert Road
Godfrey, Illinois 62035

Senate Finance Sub-Committee
Hearing of Senate Bill 2053
Testimony of Beverly Farm
Godfrey, Illinois

My name is William J. Penly, I am the father of Suzanne, a 32 year old mentally retarded daughter, and the Vice Chairman of the Board of Directors of Beverly Farm. A parent owned facility located in Godfrey, IL where developmental care is provided to 400 happy, mentally handicapped children and adults. My comments today are based on my experiences as a parent, and my experiences from having served in various capacities for 20 years in the operation of Beverly Farm.

I appreciate this opportunity to present to you the seriousness of withdrawing funds from institutions, in fact closing them, without regard to the quality or role they play in making life meaningful for over 123,000 mentally retarded citizens.

My training as an engineer has taught me to first study all aspects of the problem before adopting a solution. There is strong evidence that this bill was not conceived on this premise. I urge this committee to fully investigate the problem areas in this discriminating legislation. To do otherwise would be criminal and negligent. Thereby, failing the mentally retarded who most need the best professional help and support of the government.

It has been said, "Idealism increases in direct proportion to ones' distance from the problem". Let's get closer to the problems that must be dealt with and achieved in any government supported program. Each of the following should be analyzed in depth and legislation adopted that only fully meets these criterias.

1. The rights of all citizens to equal treatment.
2. Quality development care for all.
3. Safe physical care.
4. Permanency
5. Affordable

Before commenting specifically on each of the above objectives the following general comments are offered. First, we are not opposed to community facility living, nor do we favor large institutions. We do believe there is a need for both. Regardless of size, any facility should be properly operated as a developmental center, with a wide range of programs, services, and recreation.

Secondly, it is readily apparent that the problems involved in the care of the retarded are very complex and it is naive to think the answer lies in one and only one solution.

Third, the advocates of this legislation contend community facility living provides better care for all regardless of severity of retardation or disability, and for less cost. If true, is it necessary to advance community facilities by destroying all other methods which provide developmental care? The proposed legislation S 2053 answers this question in the affirmative. It is this reason,we who have responsibilities for daily care are so concerned. In fact, we strongly oppose this dangerous and ill conceived legislation.

The proponents may have had good intention in dictating only one concept but they failed to conceive or visualize the broad spectum of problems in caring for the retarded. They have left more voids than benefits and the following comments on the above 5 objectives address these ommissions.

1.. On individuals' rights - The need to protect a citizen's rights, is the American way, and should not require any comments. This proposed legislation is discriminatory in favor of a select few who are fortunate enough to fit into the standards compatible with community residential living. It completely ignores those with more severe problems who need it the most. Would you allow a public fire department to protect only single family residents and deny the same protection to persons living in apartments? Of course not. Similarly you should demand the same support and assistance to all handicapped persons regardless of where they reside for developmental care. The proposed legislation camouflages this discriminatory act by establishing a pitifully inadequate transition time ~~and~~ without any assurance the proposed commitments are feasible. It is shocking that this basic principle is so blantantly ignored.

The proponents of this bill state their objective is to phase out all care that does not fit their definition of community living facilities. What makes their difinition right? Beverly Farm, a home for 400 mentally retarded, is surrounded by residential homes, with no barriers. It is recognized and receives considerable support from the administration and the citizens of the city of Godfrey. Local citizens have established an organization titled, "Friends of Beverly Farm", which has contributed much in time and monies to make Beverly Farm an integral part of the community. Volunteers have organized scout troops, churches offer choir training and bell ringing, etc. In particular this selfless spontaneous response provides opportunities for the handicapped to associate with non-disabled persons in a relaxed environment without frustrations or pressures. At the same time it contributes to personal interactions with their friends. When you see the happy faces, how can anyone say 8 to 10 is better? It is doubtful if fragmented and dispersed homes could produce the same high degree of collective community awareness and support.

The proponents of this bill presume all large health care facilities are bad, and small units are good. We challenge this statement. It is no more logical than stating all tall people are bad and short people are good, so let's get rid of all tall people.

2. Quality developmental care for all - The majority of parents of the 400 residents at Beverly Farm can assure you from personal experience, that after examining the full spectrum of care facilities, they decided on Beverly Farm for the care of their loved one, not because of the size, but because of the type of care, and the opportunities offered to develop his or her personality. The programs offered are so varied, that each resident participates regardless of degree of handicap or age. Currently the age varies from 5 to 85. They actively participate daily in programs focused on his or her needs. What he does rather than what he lacks.

Beverly Farm provides therapy, medical care, psychological, speech, recreation, vocational training etc. None of which can be provided in small facilities of 8 to 10. It is too appalling to imagine that the government would propose phazing out this facility that offers so much in development and loving compassionate care.

The subject of what is best for growth and development of the retarded has been studied by experts with varing conclusions and opinions. These have frequently changed when theory is applied in actual practice. We will continue to have this pattern repeated as we progress to better care. It is pointed out that larger social groups offer more flexibility than small facilities, in implementing new developmental programs and discarding those that prove to not have merit or benefits.

Beverly Farm, founded in 1897, has proven its excellency by surviving these 87 years when it has always been a matter of choice. This is contrary to the proposed legislation that can only advance the community residential facilities by eliminating all other choices. This concept is so discriminatory and dangerous we do not believe this proposed legislation can even be used as a framework for discussions in providing better care to the retarded.

3. Safe physical care - I mention this important criteria because it is not normally available in small residential homes, such as, fire protection, freedom of barriers, and health services. In Beverly Farm and larger facilities, these safe guards are the norm. Sprinkler systems meet NFPA codes, doors and corridors are extra wide to accommodate those with low or even no mobility, side walks are wider, easy access to all buildings, etc.

In addition Beverly Farm has a comprehensive health service program including, a Medical Director, highly qualified nursing staff, physical and speech therapy, and dental care. All on the campus. The cost of similar physical protection and health care in small units becomes excessively expensive.

4. Permanency - The major concern of all parents of retarded children is "how will their loved ones be cared for after they are gone"? Beverly Farm

has provided a permanent home for the retarded for over 87 years. Three years ago a resident passed away that came to Beverly Farm in 1897. We currently have 40 residents who no longer have living relatives. This is not only comforting to the parents, but is essential to the residents, who have developed a companionship of like individuals.

The Nashville Tennessean newspaper on February 5, 1984 carried a feature story on a couple who became foster parents to four retarded children when a community home closed because of "funding problems". Larger facilities with a broader base of support are more stable and less apt to close at the drop of a hat.

Even with adequate funding can you be assured community acceptance will let you achieve high quality residential environments. It is inconceivable that anyone would phase out an existing high quality facility until this problem has been resolved. The possibility of ending up with no provision for thousands is real.

5. Affordable - We must face reality and constraints imposed by the limits of monies available regardless of the source. Rather than engage in a speculative dialogue on relative costs we will provide you with the actual costs at Beverly Farm. You can then make a comparison with actual costs of operating a community residential facility of 10 or less, being sure to include the same support costs in community homes, offered at Beverly Farm.

In the first place, Beverly Farm facilities valued at over $7,000,000 were built exclusively with private funds. We are just completing a $1,2000,000 residential building with monies raised by parents' sacrifices. The need for this building was dictated by the government and now before it is occupied, this legislation wants to close it. Not because of the quality of care and equipment, but because it is too large.

This years operating budget is at a cost of $12,000 per resident per year and over half of that is privately funded. Stated differently the average government support cost is $6,000 per resident per year. Are community residences costing less? Beverly Farm's costs are low for the services, programs, and care offered because parents take an active personal interest in the operation and they assure monies are only spent for the benefit of the resident.

The National Association of State Mental Retardation Program Directors (NASMRPD). had estimated conservatively that the initial capital investment would be $12 billion. This lesiglation provides zero dollars. That is tantamount to voluntarily jumping out of an airplane without a parachute.

In addition is,this bill places an immediate and devastating impact on privately supported facilities. Contribution would soon cease with the enactment of the Bill. Contributors would rightly conclude needed plant and operation support would be without purpose for a facility with no future.

This proposed bill has no provisions for funding the training requirements, added cost during transition, and the list goes on. It is obvious that the bill must be defeated. We are dealing with live people and we cannot start from a negative position by destroying one part of the system until other productive alternatives are in place.

In summary this proposal Senate Bill 2053 is counter productive and we respectfully request that you defeat this unacceptable bill.

Sincerely,

William J. Penly
Vice Chairman of the Board
Beverly Farm Foundation

WJP:pr

Re: Senate Bill S.2053
"Community and Family Living Amendment of 1983"
Hearing date February 27, 1984

Beverly Farm is a residential home for mentally retarded. It is a not-for-profit corporation located in Godfrey, Illinois. It is owned and operated by the parents of children residing there.

Beverly Farm was started by Dr. and Mrs. William Smith in 1897. Their son, Dr. Groves B. Smith, took over management of the Farm in 1928. Due to serious illness, Dr. Smith sold the Farm to the parents in 1958. The Farm consisted of 16 buildings and equipment. The parents have since added 10 new buildings at a cost of three million dollars financed completely within the Beverly Farm family and its friends via contributions. Beverly Farm has no debt.

Dr. Groves Smith described Beverly Farm as a little world within the larger world, where competition is lessened, the pace is slower, and security and acceptance are felt by each child. This philosophy has been carefully nurtured by the parents.

In an atmosphere of kindness, patience, and loving care the 400 residents are able to pursue the maximum of their abilities without the frustration of being forced to try to perform at levels beyond their measured capabilities.

Many residents are severely retarded and also have multiple physical handicaps. They require a great amount of individual care. Beverly Farm has been the home of many of these children for most of their lives. Many residents are higher functioning and a broad range of programs offers them opportunities for growth and development.

Beverly Farm has an "Open Door" policy where visits are encouraged at any time. The campus setting permits freedom of movement for all residents. Activities include baseball, bowling, Special Olympics, visits by bus to the zoo, amusement parks, band concerts, circus, and municipal opera. Birthdays and holidays are celebrated as special occasions.

The great relationship between residents, parents, and house mothers, freedom of discussion, and lack of regimentation, provide a peace of mind to parents and a home with a spirit of love for our children.

Senate Bill S.2053 would completely destroy Beverly Farm.

Many years of hard work, dedication, sacrifice, and love have gone into the development of this home. Please don't destroy something that is good and has a long proven record by substituting something that is going to be more costly, more difficult to monitor, has not been proven as realistic on this scale, and can not possibly offer the services offered by Beverly Farm.

Moving these residents from their home, separating them from friends of many years and completely uprooting their relationship with the people who have been caring for them for most of their lives can have a devastating effect on their lives. Please do not permit this to happen.

Your opposition to Senate Bill S.2053 is respectfully requested.

Sincerely,

William R. Black
William R. Black
Chairman of the Board
Beverly Farm
(Father of a mentally retarded
son, David Black of Beverly Farm)

STATE OF CONNECTICUT
DEPARTMENT OF MENTAL RETARDATION
GOVERNOR'S COUNCIL ON MENTAL RETARDATION

March 12, 1984

Roderick A. DeArment, Chief Counsel
Senate Committee on Finance
Room 221
Senate Dirkson Office Building
Washington D.C. 20510

Dear Mr. DeArment:

The following represents **TESTIMONY OF THE CONNECTICUT COUNCIL ON MENTAL RETARDATION ON S 2053 - COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983.**

The Connecticut Council on Mental Retardation is an 11 member body, appointed by the Governor to advise the State Commissioner of Mental Retardation and to recommend legislation to the Governor and General Assembly.

This Council applauds any and all Congressional efforts to extend Medicaid reimbursement to a wide array of community based services and residential programs for severely handicapped persons. We recognize the serious inequities in federal funding of programs for mentally retarded people, with funding much more easily available to institutional programs than it is for community-based residential facilities and programs. However, we oppose S 2053, as currently written, because it goes too far. More specifically, we oppose the withdrawal of Medicaid reimbursement of larger residential facilities. We do so for three reasons:

1) It is sheer folly to eliminate the existing system of reimbursement to larger facilities in order to "encourage" states to provide services in the community. Why not simply provide what hasn't existed up to this time: Medicaid system that pays for community--based services? State's don't have to be forced to develop community services with Medicaid funds. They need only be enabled to do so.

2) This bill chills state investment in federal programs by punishing those states who have made good faith investments in the current Medicaid system.

   What a message the Chafee bill sends! "Tough luck," it says, "Too bad that you invested heavily in physical plan improvements in order to qualify for our old passe Medicaid reimbursement system. No matter that it was the only program option available at the time. Too bad we haven't fully amortized your capital expenditures like we promised. The rules of the game have

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changed now. We don't like those big facilities anymore. If you want federal funding you'll have to replace them with the latest Congressional gimmick - the family size community residence. Will we change our minds again a few years down the road? Probably not, but only time will tell."

3) There is little, if any, empirical evidence that ALL severely disabled persons would be better served in small community facilities. It would be highly irresponsible for Congress to eliminate funding of a wide range of residential alternatives for those who would benefit from them in order to support the group home rhetoric.

Essentially, the proponents of this bill seek to eliminate funding from institutions because they feel that institutions are utilized too heavily. But the net result of their proposal would be overuse of small community facilities. Group homes aren't for everyone either.

A better, more rational, solution would be to provide for reimbursement of a wide range of residential programs, but to require and fund a state screening and monitoring system to ensure that clients receive only that level of care which their needs dictate. Funding would be contingent upon appropriate placement which could be neither too restrictive or too unstructured. This system, too, would have to be phased in as the proper mix of alternatives for individuals has not yet been completely developed in most or all states.

In summary, the Council on Mental Retardation believes that the community focus of S 2053 is laudable but the bill goes much further than is necessary or wise if its goal is to increase community service options for severely handicapped persons. The amendments should be redrafted to create fiscal incentives for states to develop community-based programs. Given such incentives, we are certain that states will accelerate that already established trend toward development of smaller homelike residential options and services at the local level. And states will also make use of any available funds to develop services to support families in caring for their disabled members and to permit handicapped persons to live as independently as possible.

We support the inclusion of state screening processes to ensure appropriate placement and of close federal monitoring of state use of Medicaid funds under this program. But we vehemently oppose the statutory disenfranchisement of thousands of people in larger facilities which is threatened by the current Chafee amendments. It is not wise, it is not human, and it is not necessary.

Sincerely,

Herbert Barall

Herbert Barall, Chairman
Governor's Council on Mental Retardation

HD:C:eac
cc: Council members

C Rec

2/8/84

Roderick De Arment
Chief Counsel
Sub-Committee on Health
Senate Committee on Finance
Washington, D.C. 20510

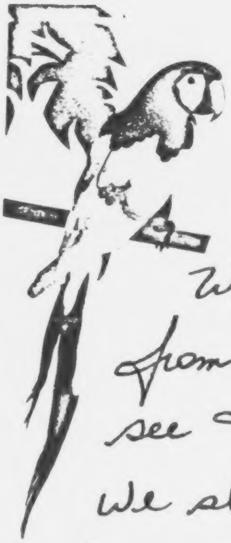
Dear Sir:

We would appreciate the following letter considered as testimony for opposition to Senate Bill 2053.

We have a 14 year old daughter, deaf & retarded, living at Misericordia Home, 6300 N. Ridge, Chicago Il 60660. Wendie, a very difficult child to control, has had the finest schooling, the finest homelife and a tremendous amount of love. She lived at home 13 years & moved to Misericordia a little over a year ago. She moved

because as a family We
Could no longer protect
her from the environment.
We worried about abduction,
rape, her World being so
silent & no way to Call out.
She had no friends, after School
Closed. The neighborhood children
tried, but she knew she was very
different. We Watched Weedie
withdraw, a happy child become
sad & angry.

Misericordia opened their
arms to our little girl. She has
friends all around that Speak in
sign. She is protected by a bus
going to & from her "special School,"
Walls around the Courtyard, Nuns



that show love in every way - all of the time.

Wendie is only 20 minutes from our home. We get to see & touch her often. Yet we sleep at night knowing tomorrow is another safe & Wonderful day for our only daughter.

Where will she go at 21 years. Its obvious the world will not be ready for a child with a sexy body, brain of a 4 year old, no voice, & no hearing. No protection from weird people, Cars, horns she cannot hear, and a 4 year olds dreams.

4

Misericordia has offered Wendie a home - Please don't try to change & endanger her life with S 2053. Please give her a "Right to Life" a "Special Safe Right to Life" Don't sell our child to the streets! Make our world Safety first - then idealism...

Sincerely,
Dr & Mrs Glenn Cabin

Dr. & Mrs. Glenn I. Cabin
6421 Hoffman
Morton Grove, IL 60053

January 30, 1984

Mr. Roderick DeArment
Chief Counsel and Staff Director, Committee on Finance
U. S. Senate, Room SD 219
Washington, D. C. 20510

Re: Proposed Bill # S2053 "Community and Family Living Amendments of 1983"

Dear Mr. DeArment:

I would like to go on record as being opposed to the above bill. My brother Jimmy cannot survive if the above bill becomes law! Currently, Jimmy, almost 42 years of age, resides in Wisconsin's excellent Central Center for the Developmentally Disabled in Madison. He has been there for almost 24 years. Prior to being institutionalized, he lived at home - with loving, caring parents, 2 sisters, and a brother - in the community. He was institutionalized because as we all got older, especially our parents, it became terrifyingly apparent that we as a family and the community as a whole, could not continue to care for him properly.

While we were growing up, there were many things we could not do because there were no facilities for Jimmy, many places we could not go because Jimmy was not "allowed." There were no ramps for his wheelchair to enable his passage into buildings - whether the buildings were the doctor's office, dentist's office, stores, movies, anything. If we did manage to lift his chair into any place, he was frequently subjected to stares and very cruel remarks. Now, more than 25 years later, and as a mother of 4 healthy, normal, active children, I can appreciate the monumental task my parents had in providing care for my brother. I also realize that communities (and people) today are not prepared to provide care and facilities for citizens like my brother any more than they were then.

The knowledge that he is well cared for and would be well cared for until his death, made his institutionalization bearable for our whole family. This proposed bill has destroyed this knowledge and created confusion and much consternation - not only in my family, but in other families with relatives in similar situations across the country.

Jimmy cannot sit up, walk, talk, or care for himself in any way. But he does enjoy his life at the Center tremendously. The Center provides this enjoyment - the daily, constant stimulation of lots of people and their activities would cease if he were subjected to "community living." Jimmy is in a ward with 15 other residents with similar afflictions. In addition to the aides, a nurse is on duty 24 hours a day. A doctor is always available 24 hours a day. This particular institution consists of 10 buildings interconnected by wide underground tunnels. These tunnels enable residents to move or be moved for various activities in safety. There is air conditioning; floors are heated allowing residents to lay down, crawl or roll about on special carts; there is a well equipped hospital; there is a Braces Shop-very necessary for repairs, modifications, etc. to special wheelchairs and other equipment so residents with atrophied limbs can tolerate sitting positions for several hours. All these services are right there-on the premises- where they are needed and used - not spread out over miles in many different directions as in the community. A move back into the community would greatly disrupt and disturb Jimmy's happy life and in all probability - shorten it considerably.

I thoroughly agree that some retarded belong in the community - but not all. MOST EMPHATICALLY NOT ALL! And those that are in the community need a very well educated community - not in the academic sense, but in the sense that the community is aware of the special needs of these special people. This proposed bill, if enacted, will undoubtedly go the way of the Foster Care program, people will volunteer, strictly for the money. Our country's existing social and law enforcement agencies (at any level-federal, state, local) cannot effectively police that program and provide a safe environment for "normal" citizens, how can they be expected to effectively police a program for the retarded. Exploitation at its worst will be the name of the game.

I ask that your committee investigate and understand the plight of the profoundly through the mildly mentally retarded much more thoroughly before taking any further action on this bill. Investigate the "burn out" rate of doctors, nurses, aides, and others who work with these people. It is the highest burn out rate known. Investigate too, the cost of moving them into the community. Many new housing units will have to be constructed. In order to convert existing houses to suit their needs, many expensive modifications will be needed on each dwelling. The cost will be staggering. The strain on the existing community services and to the taxpayer, whose taxes (federal, state, and local) will rise appreciably in order to pay for the training and salaries of the additional personnel that will be necessary. And what becomes of the existing facilities-that our tax dollars have already paid for? Please investigate the future of these empty buildings that cover acres in each state. Will the buildings be demolished and the acreage used? In what way, by whom, at whose expense, at whose profit?

Please visit several different states institutions for the mentally retarded. Some states have very poor facilities indeed. But on the other hand, states like Wisconsin, Michigan, and Minnesota have excellent facilities and should not be closed down, federal funding limited, or penalized in any way because of the poor administrations and/or lack of state funding in other states. Institutions, like people, should be judged on their individual merits or faults.

This bill denies the retarded and/or handicapped, their parents and/or guardians, the choice of institutional or community living. This bill forces all back into the community whether they want it or not, whether to their benefit or not, and whether to the community's benefit or not. A very large portion of our tax dollars are presently appropriated to social welfare programs. Much of this goes towards assistance (in some form) for those who are physically and mentally able to care for themselves. It appears to me that perhaps a better target for funding cuts can be found, while we as a society continue to support and provide for the truly needy.

Sincerely,

Gail M. Daniello

Gail M. Daniello
RR #5, Box 585, Rt. 37
New Fairfield, CT 06812
(203) 746-9867

STATEMENT
OF
DIXON ASSOCIATION FOR RETARDED CITIZENS
IN OPPOSITION TO
UNITED STATES SENATE BILL 2053
SUBMITTED TO
SENATE FINANCE COMMITTEE
SUBCOMMITTEE ON HEALTH

By way of introduction, DARC is a non-profit organization composed of parents, relatives, guardians and friends of residents of the Dixon Developmental Center. Our organization is 34 years old and has as its primary purpose promoting the general welfare of the mentally retarded, wherever they may be, and particularly those multiple handicapped at the Dixon Developmental Center.

The Dixon Developmental Center is located in Dixon, Illinois, a community of approximately 16,000 persons and, as you know, the hometown of President Reagan. The current population of the Dixon Developmental Center consists of 109 multiple handicapped, developmentally disabled individuals, the youngest of which is seventeen years of age.

The following chart summarizes the multiple handicaps which are encountered by this population of 109 residents at the Dixon Developmental Center.

DISABILITIES

POPULATION			MENTAL RETARDATION				SEIZURE DISORDERS	
Male	Female	Total	Mild	Moderate	Severe	Profound	Controlled	Not Controlled
73	36	109	13	22	11	62	18	13

AUTISM		CEREBRAL PALSY		
Mild or Moderate	Severe	Mild	Moderate	Severe
1	0	14	7	0

HEARING IMPAIRMENT		VISION IMPAIRMENT		OTHER
Hard-of Hearing	Deaf	Impaired	Blind	Normal Intel.
60	15	6	30	1

The dominant group in this multiple handicapped setting are the deaf, 41 residents, and the deaf-blind, 28 residents. However, what is important is the recognition that each of these individuals has, at a minimum, two handicaps, of which severe mental retardation is just one. In essence, you are dealing with the severely retarded multiple handicapped, developmentally disabled.

Our purpose here today is to give testimony opposing Senate Bill 2053. Upon review of Senate Bill 2053, one draws the conclusion that it is dedicated to ultimately closing down all state and private institutions for the mentally retarded having more than ten individuals. In this regard, we quote Senator Dave Durenberger: "S. 2053 would seek to provide more individualized services for the severely disabled by shifting federal medicaid funds from institutions for the disabled, primarily intermediate care facilities (ICF's) and ICF's for the mentally retarded, to community-based settings." While this may be a desired effect by some, without medicaid funds, any institutional facility for the mentally retarded could only provide custodial care and none of the programs that are necessary for the well-being of their residents. In effect, these institutions become warehouses and set back to the Middle-Ages the cause of the mentally retarded.

The Dixon Association for Retarded Citizens has not opposed the moving of residents into "Community Facilities," but has been insistent that these facilities provide the appropriate programmatic and habilitative needs of the resident. However, experience has demonstrated that those who are able to function in "Community Facilities" are the mildly retarded. Further, these facilities are programmed, designed and staffed to meet the needs of such individuals. In the case of the more severely retarded multiple handicapped, the experience is different.

When Governor Thompson, in January of 1982, announced the conversion of the Dixon Developmental Center (DDC) into a prison, the Illinois Association for Retarded Citizens, through its directors, attempted to assure the parents at DDC that there were one thousand beds available in the community to take care of the residents. Many parents of DDC residents were not impressed with these pronouncements and turned to the courts for assistance.

The end result of the legal maneuverings was that the Department of Mental Health and Developmental Disabilities recognized its responsibilities in this matter and implemented a process which ensured that the retarded multiple handicapped residing at Dixon, except for the deaf, deaf-blind, and a few other severely retarded multiple handicapped, were placed in appropriate settings which met their programmatic and habilitative requirements. Respectfully, we point out to this Senate Committee that of the approximately seven hundred residents transferred, only twenty-five were able to be placed in "Community Facilities," or approximately 3.5 percent; the remaining were moved to other state facilities.

This case alone demonstrates the inability of "Community Facilities" to meet the programmatic and habilitative needs of the retarded multiple handicapped. The Association for Retarded Citizens (National) and Illinois Association for Retarded Citizens do not seem to recognize and appear determined to ignore the fact that community living facilities do not meet the needs of a substantial number of the retarded multiple handicapped. The facts point out that these people need a highly trained staff and dynamic programs within a protective setting. At this point, and with all due respect to the parties involved, we must point out that in this most serious matter the Association for Retarded Citizens (National), one of the driving forces behind this bill, does not speak for us nor for an overwhelming number of the multiple handicapped, developmentally disabled.

One of the outstanding areas of the Dixon Developmental Center was the development of a program for the deaf and deaf-blind retarded. This program had gained national attention and had been looked upon by others as a model program. When Governor Thompson gave his statement on the conversion of the Dixon Developmental Center into a prison, he also noted the unique qualities of this program and announced that it would remain in Dixon and be housed in a new facility.

The decision of Governor Thompson to retain this specialized population at Dixon was based on the multiple needs of the severly and profoundly, developmentally disabled deaf and deaf-blind individuals currently residing at this facility for whom there is no appropriate alternative residential placement.

At the present time, the Department of Mental Health and Developmental Disabilities is proceeding with the development of a new facility in Dixon which will be used as a state resource in developing programs for the deaf and deaf-blind retarded. This facility will be built on a lovely 16-acre site which will contain one administration building and seven residences, each complete with dining, recreational and specialized training rooms, and each housing sixteen persons.

This new facility is specifically designed for small individualized groupings in a more normalized living environment. Since these residential buildings are clustered, it is possible to maintain the large group of specialized training staff who are necessary to meet the needs of these residents. It would have been economically prohibitive and impossible to maintain this program and core of highly specialized staff had the housing of these residents been scattered over a larger geographical area.

When the conversion of the Dixon Developmental Center was announced, the State of Illinois and the American Federation of State, County and Municipal Employees Union met to discuss the deaf and deaf-blind program. These meetings resulted in retaining the specialized staff, which provided direct care services to these individuals, outside the normal layoff process (last hired - first fired). The principles involved in this decision were that these individuals had, had years of specialized training and experience in working with the deaf and deaf-blind, severely and profoundly mentally retarded individuals.

Nowhere else in the state is there such a concentration of staff with the specialized education and dedication to meet these needs. This staff training not only includes providing basic care needs for the severely and profoundly, developmentally disabled individual, but also specialized training in manual communication for the deaf and deaf-blind, which, incidentally, all the staff have.

The Dixon Developmental Center, in a residential setting, is structured by the principles of normalization and provides habilitative training in the areas of self-help skills, maladaptive behavior reduction, communication skills, gross and fine motor skills, socialization skills and independent living skills within a protective environment. The programs used for this training have been specifically designed for use with the deaf and deaf-blind impaired, developmentally disabled population and have been refined over the course of several years.

The Dixon Developmental Center staff responsible for the provision of habilitative services, include two administrators (with clinical backgrounds in social work and nursing), a psychologist, a registered nurse, a social worker, two activity therapists, a speech pathologist, an audiologist and a mental health specialist, as well as a specially trained and highly dedicated group of mental health technicians.

In addition, Dixon Developmental Center recipients, where appropriate, are enrolled in programs at Krieder Services, Inc., a CARF accredited organization, in the areas of day care, work activity and workshop programs, thus providing a coordinated hierarchical continuum of habilitative service.

The late professor of psychology Abraham Maslow set forth what he considered five levels of human needs, and it is appropriate that we examine these needs and how they are fulfilled at the Dixon Developmental Center.

Level 1: PHYSIOLOGICAL NEEDS

Examples: Hunger, Thirst, Sleep, and Waste Elimination.

The deaf and deaf-blind multiple handicapped need special assistance to assure that these needs are met - these needs have been met at the Dixon Developmental Center because of the specialized training given the staff in both manual communication and sensitivity to the problems of the multiple handicapped deaf and deaf-blind.

Level 2: THE NEED FOR SAFETY AND SECURITY

Examples: Safe Shelter, a Sense of Home, Security from Physical Threats and Loss of Property, and Familiar Surroundings.

The deaf and deaf-blind multiple handicapped would be overwhelmed in an urban surrounding - yet he or she can attain this level within the protective setting of the Dixon Developmental Center.

Level 3: THE NEED FOR LOVE AND BELONGINGNESS

Examples: Companionship, the Care by Others, Social Adaptation, and the Caring for Others.

The deaf and deaf-blind multiple handicapped are able to achieve this level with their own peers, and staff that can relate to their special needs, as well as their families. A "Community Facility" could not provide the interaction of a homogeneous group nor the specialized staff to meet these needs - both of which exist at the Dixon Developmental Center.

Level 4: THE NEED FOR ESTEEM

Examples: Self-Respect and Personal Adequacy.

The deaf and deaf-blind multiple handicapped find this in workshop programs and group activities specifically designed to meet their special requirements - these programs are in an action mode at the Dixon Developmental Center.

In the heterogeneous setting most likely to be found in a "Community Facility," it would be almost impossible to find equivalent programs for the deaf and deaf-blind multiple handicapped.

Level 5: THE NEED FOR SELF-ACTUALIZATION

Examples: Accomplishment of Useful Tasks; e.g., Making One's Bed, Washing One's Clothes, and Brushing of Teeth.

The deaf and deaf-blind multiple handicapped can learn these skills in a collective setting and under the supervision of specially trained personnel. The deaf and deaf-blind multiple handicapped are able to sense accomplishment when performing these tasks in front of their own peers. The Dixon Developmental Center offers the setting and dedication for the fulfillment of this level.

Students of human behavior would generally agree that an individual who achieved these levels of human needs would adjust to his or her setting and that this adjustment will be even greater if that individual has won the respect of his or her peers.

In the case of the deaf, deaf-blind and other severely retarded multiple handicapped, their peers are similarly low incident handicapped - not us.

In conclusion, the passage of Senate Bill 2053 would destroy this tremendous program and obliterate whatever progress these individuals may have made toward attaining their dignity.

Therefore, we oppose passage of Senate Bill 2053.

Thank you.

Nicholas J. De Leonardis, President
Dixon Association for Retarded Citizens

STATEMENT OF LEONA FIALKOWSKI IN SUPPORT OF S.2053

I am Leona Fialkowski of 5113 James Street, Philadelphia. I wish to have my statement in support of S.2053 made part of the record of the Hearings held on S.2053, the Community and Family Living Amendments Act.

I had the opportunity to attend the hearings on S.2053, and listen to the testimony of the experts and professionals on the complex issues surrounding services for disabled and retarded persons. I would like you to consider as well the views of parents, who have attempted over a long period of time, to secure appropriate services for their children. I am not a professional, I have no degrees or credentials, but from my life experience I believe I qualify as an expert in parenting and the parent's struggle to obtain appropriate services. I am 60 years old and with my husband, now retired, have brought up 10 children. Two of my sons, Walter and David, are severely handicapped. David, age 22 who is still at home, will "graduate" from high school next year. Walter, age 32, lives nearby in a community residence, and attends a workshop in Northeast Philadelphia.

When David and Walter were of school age, there was no public school for them. If I wanted "education", my only choice was an institution far from home. I did not know much about institutions in those days, but I did know that I did not want my sons separated from their family. With no public school services available, we started our own school for children with severe handicaps. Finally, as a result of Court action and the enactment of federal law P. L. 94-142, David and Walter were accepted into public school.

While I was always concerned with the quality of education for my sons, as they grew older I fully realized that the equally important question was: "where do they go after they finish school". For children as severely handicapped as Walter and David, the likely answer was an institution. Throughout my years of advocating for my children and working with parents I came to know institutions. I know the worst, like Pennhurst, where I served as a parent advocate for residents; and I know the so-called good institutions such as Woodhaven, where I serve on the Board of Trustees. Despite all the professional debate about improving institutions, it takes little more than a parent's common sense to know that no institution is a substitute for home and family. Parents have used institutions as a last resort because there are no other alternatives.

As a parent who has struggled to keep our sons in the family with us, and as a taxpayer, I am angry and upset when I learn that my federal taxes go to support ICF institutions but not for in-home support or community services. If I choose to place my two sons in Woodhaven, an ICF institution for 300 developmentally disabled persons in Philadelphia, it would cost at current ICF Medicaid rates over $180.00 a day for each, or over $131,000 a year for both. The federal government would pick up more than half the cost. On the other hand, if I want to keep my family together and in the community, I and other parents must make do on our own and be continually told, "there is no money, there are no programs, only waiting lists." If we could have just a fraction of what the federal government is willing to spend if we institutionalize our children, local communities could support severely handicapped children and adults at home and in the community. My sons are now young men. Many parents of younger severely handicapped children, who thanks to Congress have never been excluded from school programs, do not realize what is waiting for them after the school years. If Congress does not enact S.2053 or similar legislation, the future will be more institutions, separated families, and a waste of the years of investment in education of our handicapped youngsters.

I urge you not to let S.2053 die. If there are problems with the bill, correct them; but do not abandon those families who have sacrificed in the past and urgently need support now.

Thank you for your consideration of my view.

February 20, 1984

To: Mr. Roderick A. De Arment, Chief Counsel
Senate Committee on Finance SD 219
Dirksen Office Bldg.
Washington, D. C. 20510

We are opposed to Senate Bill 2053 which disciminates against profoundly retarded people and their parents and guardians because:

1. It denies them the right to select the most normalizing residential services in the community.
2. It denies states such as Wisconsin, which have superior institutional programs, the right to provide a continuum of care for all retarded people.
3. It denies Medicaid funding to states, such as Wisconsin, which have been responsible in the use of that money.

In conclusion: Between us we have had 67 years of service in the Milwaukee Public Schools as teachers of special and academic classes, counselors to disadvantaged pupils, and as administrators; we know from experience the compassionate and educational programs available to the largest number of retarded people in the community.

Sincerely yours,

Fred C Gee

(Mr. and Mrs. Fred C. Gee)
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DEPARTMENT OF PEDIATRICS
Infectious Diseases and Immunology
JOSEPH A. BELLANTI, M.D.

Introduction

I am Joseph A. Bellanti, M.D., a Professor of Pediatrics and Microbiology at Georgetown University School of Medicine. For the past 20 years I have been engaged in research, education and patient care activities related to children. I this capacity I have provided care for hundreds of children with various forms of chronic handicapping conditions, including mental retardation. Many of these children have been referred from residential institutions, such as Great Oaks facility in Maryland, which have provided quality care to these children, many of whom are severely and profundly mentally retarded. Included within this testimony is a basis for my recommendation to the Subcommittee that both residential institutions and community facilities are needed in a comprehensive system of care for the mentally retarded. The following is a summary of the principal points included in this statement:

- Changing trends of placement of mentally retarded persons from public institutions to residential placements in the community.

- Medical need for institutions in providing care for these most seriously involved - a need which cannot be met by residential placements in the community.

- Need for a diversified approach of care for the mentally retarded involving alternative facilities for the mentally retarded in response to the wide spectrum of severity of mental retardation ranging from minimal involvement to those who are severely and profoundly affected.

- Reduction of medical and related services for mentally retarded would not be cost-effective.

- The record of community facilities thus far is not reassuring.

- Will group homes envisaged by S. 2053 fall heir to the ills of the nursing homes?

- Conclusion - the need for diversification of health care facilities for the mentally retarded.

1. Background: institutional and community oriented residential facilities for the mentally retarded

In 1971, a Presidential Statement on Mental Retardation established a goal of placing one-third of some 200,000 mentally retarded persons in public institutions in residential placements in the community. The goal was based on public recognition that large numbers of persons living in overcrowded conditions in underfinanced public institutions might be better able to lead richer and more rewarding lives in smaller residential settings in the community. By June 1979 the number in such institutions had decreased to about 140,000 and in 1982 this number had further declined to about 119,000. At the same time the number of mentally retarded persons living in community based residential facilities increased from about 600 facilities housing over 9,000 persons to nearly 5,000 facilities housing 62,000 persons.1/

While this goal was in the process of realization, Congress also recognized the basic medical reality that residential institutions will continue to be needed in the spectrum of services that must be available for the mentally retarded. As Senator Allan Cranston noted of the bill which became the Developmental Disabilities Act, that bill:

> "***recognize[d] that the need for some long-term residential programs will remain. The bill specifically provides that where institutional programs are appropriate, adequate support should be planned for them so that the necessary treatment and

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1/ Longitudinal Study of Court-Ordered Deinstitutionalization of Pennhurst Residents (Dec. 15, 1983). Federal funding helped play a part:

> "Federal housing assistance programs can be successfully used to fund many of the types of housing in the community needed by mentally disabled persons. Although housing assistance legislation was amended in 1974 to authorize assistance to mentally disabled persons, surprisingly little federally funded housing has actually been extended to this population. The money is available, however, and many of the roadblocks which have traditionally prevented its use to fund needed housing for disabled persons gradually are being removed."

Yohalem, "Federal Housing Programs for the Mentally Disabled," 2 PLI Legal Rights of Mentally Disabled Persons 1745 (1979).

> habilitation programs can be given residential patients to develop their full potential."[1]

2. A medical need for institutions for those most seriously involved

Congressional recognition of the continuing role that institutions for the mentally retarded must play is based on some harsh medical facts. While many retarded persons are endowed with the good health that may allow them to function well in the community, there are tens of thousands of others who regrettably are in a very different category. Crippled, non-ambulatory, seizure-prone, unable to feed themselves or attend to their basic needs, blind, deaf and without language, these persons are in constant need of medical surveillance and attention. It is a tragic fact that among a substantial proportion of the mentally retarded, nature has not been content to visit only a single handicap upon its victims. It has all too often struck with catastrophic effect and plagued these people with multiple deficits. These occurrences are so frequent that careful physicians who find themselves in the presence of one handicap, whether at birth or subsequently, especially if manifested in severe or profound form, will routinely search for a syndrome of handicaps and problems. This phenomenon has long been recognized and is commonly reflected in surveys of the handicapped population.

Now the innate deficits that may be discovered in many mentally retarded persons do not unfortunately exhaust the catalogue of illness to which they are subject. They are at higher risk than the general population to the ravages of infectious diseases as well. To take but one example, the incidence and mortality of respiratory disease in the retarded is higher than in the general population and it is greater in the more severely retarded than in the less retarded. Of all causes of death among the retarded, respiratory disease has been documented as the most frequent, especially in the profoundly mentally retarded. The differences between the death rates for the profoundly mentally retarded and other retarded persons in comparison to those rates for the U.S. population as a whole are especially striking. Thus one study1/ disclosed the following comparisons:

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[1] 121 Cong. Rec. 16520 (1975).

Age - standardized death rates/1000

	All deaths	Resp. deaths	Respiratory-specific death ratios
Profoundly mentally retarded	40	27	66.7
Other mentally retarded	15	9	50.1
U S.A.	9.5	0.4	4.2

The study noted that profound retardation was at particularly outstanding risk when in combination with epilepsy, inability to ambulate, and developmental cranial anomalies.

1/ Chaney, Eyman, Miller, "Comparison of Respiratory Mortality in the Profoundly Mentally Retarded and in the Less Retarded," 23 Journ. of Mental Deficiency 1 (1979).

This state of affairs is but one indicium of the need of a substantial class of mentally retarded persons for a medically adequate setting.

3. Recognition of the need for a diversified approach involving alternative facilities for the mentally retarded

It has long been recognized by professionals and others concerned with the problems of the mentally retarded and other developmentally disabled1/ that these labels do not describe a single homogeneous class. Rather they apply to a large number of disparate individuals whose needs require a spectrum of alternatives rather than a single panacea, however beguiling its appeal. Phillip Roos, a former Executive Director of the National Association for Retarded Children (now Citizens), has written:2/

> "***We must develop alternative plans and solutions, resisting the temptation of simplifying life by selecting a single answer to a problem.***"
>
> "If we are to capitalize on this liberalizing trend in our society, we must, of course, expand differentiated service options so that selection among varied desirable alternatives is indeed possible. Adequate funding is, of course, essential. However, it is not sufficient. Standards and regulations which determine funding patterns must encourage alternative service models. We are tempted to adopt simplistic answers and to encourage simple solutions while eliminating options. For instance, there are voices raised today which clamor for the complete abolition of residential institutions. Based on the deplorable conditions currently existing in many institutions, the temptation is indeed great to eliminate this possible

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1/ The term "developmental disability" is defined at 42 U.S.C. §6001(7) and includes mental retardation, cerebral palsy, epilepsy, autism and learning disabilities.

2/ Roos, "Mentally Retarded Citizens: Challenges for the 1970's," 23 Syracuse Law Review 1059, 1060, 1063, 1065 (1972).

> alternative. Yet this solution is simplistic and is based on emotional rather than on rational grounds. If we are to capitalize on diversification we need to expand rather than curtail possible alternative solutions."

Elizabeth M. Boggs, a former president of the same organization, has also stressed the need for a multifaceted approach to the needs of the mentally retarded:

> "***Successful societies are students of ergonomics; they fit the habitat to the inhabitants. If the inhabitants differ from one another, then so should the habitats and even the subcultures, ethnic or otherwise. In an era of divergent life styles, it seems particularly ironic that we place such stress on normalization for the retarded. Somehow the gap between public policy and private preferences seems great at times. Social reforms based on theoretical constructs are still pursued with the same missionary zeal as was the eugenics movement in times past."1/

The need for a diversity of approaches that is stressed by both Mr. Roos and Mrs. Boggs requires recognition that the needs of the more medically involved retarded must never be sacrificed in order to advance the cause of those more advantaged in health.

4. Cost savings should not be realized by reducing medical and related services

If health requirements for the most disadvantaged among the retarded cannot be sacrified to ideology, should they be sacrificed to the more mundane concerns of cost? Advocates of wholesale deinstitutionalization have been joined by those who see in the movement the possibility of conserving public revenues. A number of studies has been conducted to ascertain the costs of public and community residential facilities but they are far from uniform in their conclusions:

1/ "Who is Putting Whose Head in the Sand Or in the Clouds as the Case May Be?" in Turnbull & Turnbull, Parents Speak Out 51, 64 (1978).

> "Over the past decade, there have been a number of studies the relative costs of institutional and community residential programs in an attempt to replace these presumptions with hard data. Wieck and Bruininks (1980) provide an excellent review of such studies. The results of these and more recent studies are not conclusive. Some researchers indicate lower costs for community alternatives (Murphy and Datel, 1976; Touche Ross and Company, 1980; Temple University, 1982; Ray, Blessing, Bradley and McCausland, 1982; Sullivan, Bosworth, and Nurney, 1983); others are unable to find a consistent difference in costs in favor of community programs or institutional programs (Mayeda and Wai, 1975; Jones and Jones, 1976; Templeman, Gage, and Fredricks, 1982). As noted by Wieck and Bruininks (1980, p. 17) "Opinions about the costs of residential services abound, while rigorous studies remain difficult to design, implement, and evaluate."[1]

In the Wieck and Bruininks[2] study just mentioned, another study (by Mayeda and Wai) is summarized. The latter provides a distressing clue as to the nature of the savings that might be ascribed to an exclusively community oriented approach:

> "One of the most carefully designed studies of comparisons between community and public facilities was conducted by Mayeda and Wai (1975). The model they employed aggregated costs over six direct variables and one indirect cost variable including: a) room and board, b) attendant services, c) special programs, d) educational programs, f) support services, and g) general administrative costs. By analyzing budgets of state hospitals and regional centers in California, Florida, and Washington for a six-month period in 1974 and 1975, Mayeda and Wai were able to trace and record the total costs for services provided to 4,284 community and institutional residents."

The clue emerges in the first two conclusions of the Mayeda and Wai study:

> "***The first conclusion of this study was:
>
> The cost of services to developmentally disabled persons in state hospitals does not differ significantly from the adjusted true costs of services in community settings provided both groups are provided with a full array of needed services." (underscoring supplied)

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[1] Longitudinal Study of Court-Ordered Deinstitutionalization of Pennhurst Residents 3 (dec. 15, 1983).

[2] Wieck and Bruininks, "The Cost of Public and Community Residential Care for Mentally Retarded People in the U.S. (1980).

In other words, if needed services are supplied to the mentally retarded, there is no significant cost benefit in favor of a community setting. That there may, in fact, be a cost differential arises from the fact that less services are given to those who need them in the community facilities. Nor can this be wholly ascribed to the elimination of "unnecessary" services to what is most evidently not a pampered population.

"The authors concluded:

> The service utilization patterns in community settings are lower than utilization patterns of services in state hospitals due partially to the weaknesses of the coordinating interface in community settings and differences in repayment criteria and policies." (underscoring supplied)

In short, if "savings" are to be derived from a diminishment of services that were until recently universally recognized as inadequate, then it is those least able to defend themselves who will lose out. Predictably, these will not be the more highly functioning individuals with superior health. The loss will fall disproportionately on those in precarious health and with medical complications. The result is foreseeable: With every decrease in medical and related services there will be a parallel increase in the illness, suffering and mortality of the severely and profoundly retarded.

5. Community facilities: the record thus far is not reassuring

This brings me to a consideration of how well the community facilities are in fact working, for if the nation were to decide to phase out its public residential institutions in accordance with the mandate of S. 2053, it is these facilities that would form the bulwark and standard of the new system. The conclusion can only be preliminary and tentative and I undertake it not as an adversary of community facilities but rather as one who believes that, properly constituted and regulated, they will contribute importantly to a comprehensive system of alternative facilities for the mentally retarded.

I regret to say that the conclusion is not unmixed. In the view of one objective and sympathetic observer:

> "***Only in a few states and a number of isolated communities were there the support services and commitment necessary to overcome inertia and planned opposition. Too many former residents of institutions were rendered helpless by community placements that were made without regard to the individual needs of the disabled person. Too many individuals capable of living outside the institution were never given the proper opportunity to do so. Decentralization in many instances made enforcement of the most basic humanitarian values impossible; abuses were simply allowed to go on unchecked. Even with the heartwarming examples of how deinstitutionalization, when properly supported, has worked out well, the overwhelming series of horror stories from across the United States has left a bad impression in the minds of many policymakers."1/

As far back as 1976, Butterfield had sounded an alarm:

> "***The question must be asked:
>
> > Are these released people faring better outside than they were inside the institution?"2/

He noted the lack of objective information about the quality and outcomes of care provided. More recently comprehensive inquiries have been undertaken in New York and California.

1/ "Summary and Analysis," American Bar Association Commission on the Mentally Disabled, 5 Mental Disability Law Reporter 379 (Nov.-Dec. 1981).

2/ Butterfield, in Changing Patterns in Residential Services for the Mentally Retarded, President's Committee on Mental Retardation 34 (1976).

In New York since 1967, the number of mentally retarded persons in public institutions has been reduced from 27,563 to approximately 14,000 in 1980. A study conducted by Willer and Intagliata found "***wide variations in the quality of care and a poorly planned system for determining community placements."1/ Etzioni was less cautious in his assessment.2/

1/ "Study says New York's placement of mentally retarded in community is poorly planned," A.B.A. Commission on the Mentally Disabled 5 Mental Disability Law Reporter 52 (Jan.-Feb. 1981).

2/ Referring to the fortunate who are ambulatory, he wrote:

> "For New Yorkers the 'deinstitutionalized' are familiar fixtures. On upper Broadway, for example, they line the benches of the traffic islands, next to paper bags which contain the full measure of their belongings. Others scavenge trash baskets in the Bowery, or sleep in the doorways in the Bloomingdale's area."

Moreover, in seeking the cause of a basically good idea gone wrong, he attempted to go to the heart of the matter:

> "***you can repeat after Schumacher 'small is beautiful' until all the big institutions are broken up into small ones, but please also note that the greatest abuses occur in the small ones. Thus horrid as the huge state institutions are, many 'adult' residential halls and nuring homes, in which many of the so-called 'deinstitutionalized' persons end up, are more scandal-riddled and more abusive than anyone ever charged any state institution of being. 'Small' here means even more difficult to oversee, inspect, and keep tabs on, than big, and hence even more unresponsive to reform. Also, 'small' often means run on a profitmaking basis. and these small institutions are often run not by normal businessmen, but by profiteers. As Senator Frank Moss said when he released a report on the boarding home industry, prepared by the staff of the Senate Subcommittee on Long-Term Care: 'Operators understand that the way to make a profit is to cut back on food, staff, bedding and other vital services. Whatever is not spent becomes profit."

Etzioni, "Deinstitutionalization...A Vastly Oversold Good Idea," Columbia 14, 17 (Spring 1978).

In December, 1983 California released a comprehensive study of its community care facilities. As long ago as 1975 in a study of family-care homes with six or fewer residents and board and care facilities in California, Edgerton stated:

> "Some board and care facilities are open setting which provide more nearly normalized experiences than large institutions typically do. Most, however, are closed ghetto-like places, whose residents are walled off from any access to community life. Such places frequently lack most medical, psychological, and recreational services and their amenities are few indeed. the quality of life in the alternative care facilities we have studied is highly variable, with evidence here and there of exciting progress toward the goal of normalization. For most mentally retarded people in this system, however, the little institutions where they now reside appear to be no better than the large ones from which they came, and some are manifestly worse. (pp. 130-131)"1/

The recent study of the California State Commission has gone further:

> "The first finding of this study is the most shocking: California is tolerating the operation of numerous community care facilities in deplorable conditions.2/

Now the California study was not confined to group homes for the retarded. It examined a variety of different forms of community care facilities.

1/ Edgerton, "Issues relating to the quality of life among mentally retarded persons in Begab & Richardson, The Mentally Retarded in Society (1975) quoted in Balla, "Relationship of Institution Size to Quality of Care: A Review of the Literature," 81 Am. Journ. of Mental Deficiency 117 (1976).

2/ The report continued:

> "The residents are subjected to physical and sexual abuse, neglect, and generally unsafe living conditions. As one representative of the community care industry observed, 'the conditions are far more severe than ever existed in nursing homes fifteen years ago. It's a snake pit out there.'
>
> The unfortunate difference is that few people, particularly government officials, are aware of the unconscionable conditions which thousands of community care residents, most of whom cannot care for themselves, must live in each day."

Commission on California State Government Organization and Economy, "Community Residential Care in California" (Dec. 1983) at p. 21. See also New York Times, January 16, 1984.

Of 22,000 community residential care facilities throughout the state, 18,000 (82%) were licensed for six or fewer residents. Of the latter, approximately 4,000 housed the elderly and developmentally and mentally disabled clients, while the remainder served foster care children. What united the category under study was the absence of on-site medical care:

> "It is 'nonmedical care' that places all these quite disparate care options into the single category 'community care' for purposes of licensing. The efforts of government to reduce the high costs of professional long-term care for various disabilities have led to this categorization and have thereby stimulated the demand for increasing numbers of community care beds. Individuals without medical training, but with their own homes to offer as a resource, have come forward to supply this care."

It is this aspect that particularly concerns me when I consider the plight of those retarded, especially the profoundly and severely affected, who frequently display the most medical complications and enjoy only the most fragile health. With their hold on life tenuous at best, little need be left to the imagination were their well-being to be consigned to facilities whose proprietors, however well intentioned, were distinguished by their lack of medical knowledge and skill.

6. Will the group homes envisaged by S. 2053 fall heir to the ills of the nursing homes?

To most of us the term "group home" is new. This is the colloquial description of the kind of community facility which S. 2053 would seek to establish. Because of its novelty, it may be difficult to assimilate it conceptually. One way of doing so would be to compare it briefly with facilities with which we have more familiar associations. Consider the nursing home.[1]

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[1] See Brown, "An Appraisal of the Nursing Home Enforcement Process," 17 Arizona Law Rev. 304 (1975) from which the following analysis is drawn.

There are currently in excess of 20,000 nursing homes in the United States and their revenues exceed $7 billion, of which more than one-half is public funds. Since the enactment of Medicare and Medicaid in 1965 the nursing home industry has experienced rapid growth.

Over one million people live in nursing homes and most suffer from several chronic diseases. A substantial number suffer from cerebral arteriosclerosis which restricts the flow of blood to the brain. Many of the residents must rely for help on others. Thus less than half can walk or bathe by themselves and almost a half need help in dressing. About ten per cent need help in eating. To some extent, then the problems of these persons resemble those of the severely and profoundly retarded.

As a general matter, nursing homes are facilities that provide medical services to persons who do not need the extensive medical care available in hospitals. There are two basic types of nursing homes. One type is the "skilled nursing facility." It offers 24 hour nursing care under a registered nurse's supervision. There are more than 9,000 of these facilities with almost 650,000 beds. The second type of nursing home is called an "intermediate care facility." It provides health-related care to persons who need more than bed and board but less than that which is furnished by the "skilled nursing facility." Both types of nursing homes are regulated by the Department of Health and Human Services, as well as by the states.1/

1/ There is a third facility which, although not truly a nursing home, may be borne in mind as well. It is a custodial care facility sometimes called a "bed and board home." It provides no nursing services, but only custodial services such as aid in bathing, dressing and eating. Unlike the true nursing homes, it is not eligible for reimbursement under Medicare and Medicaid and is supervised only by the states.

Professor Brown has supplied an evaluation of the nursing homes:

> "In some homes, the care we desire is provided compassionately and competently. In others, it is not. Indeed, evidence is mounting that more than half the nursing homes in this nation are abusing the public trust; patients are neglected or physically abused, their money and property is stolen, their very lives are endangered, and massive misuse of public funds is commonplace in the industry. Further, despite the nation's enormous moral and monetary investment in the nursing home industry, public agencies entrusted with the regulation of nursing homes have been ineffectual in preventing these abuses."[1]

While the nursing home is not an exact model for the "group home," certain features of the two are similar. Both would ordinarily have homogenous populations, would ordinarily be located in the community and would serve individuals (especially in the case of the severely and profoundly retarded) who need more medical and medically related care than the general population.

Although nursing homes are the recipients of substantial federal funds and the subjects of federal regulation, experience has sadly demonstrated that much is wanting in the services that they render to their residents. Now the regulatory framework is more explicit in regard to the type of medical care that must be provided to those housed in nursing homes than to the type that would be required to be provided to those who would be housed in the community facilities that would be established if S. 2053 were enacted. Nor are the means of enforcement of any federal standards that may be promulgated to implement the vague criteria of S. 2053 concerning the provision of medical care any better than those that have hitherto proved inadequate in respect of nursing homes.

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[1] *Ibid* at p. 305.

Many observers of the nursing home industry have suggested ways in which federal standards of care might be enforced.1/ S. 2053 shows no evidence that its drafters have taken notice. If the medical care mandated under S. 2053 is vaguer and the enforcement procedures no better than those already developed for nursing homes, I cannot be optimistic concerning the welfare of persons who would be transferred to the community facilities.

7. Conclusion

In conclusion, both residential institutions and community facilities are needed in a comprehensive system of care for the mentally retarded. Both need federal funding and federal regulation to assure that proper medical and other standards are observed. Neither is a complete answer in itself and they should be encouraged to play both complementary and competing roles. The latter role is as important as the former for it is only through competition that the one may serve as a quality control upon the other. The former role cannot be dispensed with as long as we recognize the harsh facts of medical reality: There are large numbers of severely and profoundly mentally retarded persons with medical complications who will always require the resources and specialized care that only a high quality institution can offer.

1/ See, e.g.: Brown, "An Appraisal of the Nursing Home Enforcement Process," 17 Ariz. Law Rev. 304 (1975); Berman, "The Nursing Home Morass," 17 Ariz. Law Rev. 357 (1975); "Governmental Regulation of Nursing Homes-An Inquiry," Utah Law Rev. 270 (1973); Kemanis, "A Critical Evaluation of the Federal Role in Nursing Home Quality Enforcement," 51 Univ. of Colorado Law Rev. 607 (1979-1980); Regan, "A Quality Assurance System in Nursing Homes," 53 Journal of Urban Law 153 (1975).

Testimony of Great Oaks Association, Inc.
# of Silver Spring, Maryland

In Response To

The Senate Finance Subcommittee on Health
On Community and Family Living Amendments
of 1983, S. 2053, Hearing

Monday
February 27, 1984
1:30 P.M.
Room SD-215
Dirksen Senate Office Building

> "Experience should teach us to be most on our guard...when the government's purposes are beneficent .... The greatest dangers to liberty lurk in insidious encroachments by men of zeal, well-meaning but without understanding." Olmstead v. United States, 277 U.S. 438, 479 (1928) (Brandeis J., dissenting)

* * * * * *

A bill (S. 2053) called "Community and Family Living Amendments of 1983" has been introduced into the U.S. Senate. Its objective is to phase out, over a period of ten to fifteen years, all institutions for the mentally retarded with more than 15 residents by taking away their federal funding. It would direct that this funding be put into small group homes instead.

We are the parents of mentally retarded persons residing at Great Oaks Center in Silver Spring, Maryland. We feel that some persons would benefit by being in group homes but that other persons need the shelter and specialized resources that only a quality institution can offer. It is our belief that, in a free society, there should be a choice of arrangements for the mentally retarded and that neither the federal government nor any one else should dictate the type of arrangements. Both institutions and group homes have their place and should be supported by federal funds, neither to the exclusion of the other. Both should be monitored, kept at a high standard and constantly improved in quality. Because S. 2053 fails to recognize these important points, we have serious reservations to that bill.

Our parents' association has taken the following resolution:

> "It is resolved that it is the opinion of the Great Oaks Association that every effort be made, including the amendment of the proposed bill (S. 2053), to preserve Great Oaks Institution and other institutions that have comparable fine quality."

In our view, an amendment to the bill would have to make clear that:

(1) institutions for the mentally retarded would not be phased out, but would continue to receive federal funding adequate for their needs and would continue to be upgraded in quality;

(2) mandatory standards of care and inspection would have to be inserted into the amended bill to assure quality care for those retarded persons who would live in community facilities;

(3) effective means of enforcement of those standards of care that were set out in the amended bill would have to be afforded, on behalf of the retarded, to both the supervisory agencies and the families of the retarded.

* * * * * *

(1) There is an important and continuing need for quality residential institutions (in addition to group homes) and, accordingly, federal funding should not be withdrawn from the institutions.

For more than a decade important progress has been made in the care of the mentally handicapped. Hundreds of million of dollars have been invested through federally assisted funding of state programs in improving residential institutions.1/ Simultaneously, large numbers of retarded persons have taken up residence in community facilities.2/ Movement to community facilities reflects the view that many retarded persons are able to profit by living in the community in small group homes. This view is, in turn, based on a belief that "normalization" is the best policy and that retarded persons should enjoy the "least restrictive conditions appropriate to their needs."

While there is general consensus on these points, differences of opinion arise concerning their implementation. Thus, Philip Roos, a former Executive Director of the National Association for Retarded Citizens, has written that

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1/ According to one estimate:

> "In order to comply with federal ICF/MR standards, states invested well over a billion dollars during the late 1970's and earlier 1980's to improve the physical plants of public institutions for the mentally retarded." National Assn. of State Mental Retardation Program Directors, Inc., Position Statement on S. 2053 at p. 4 (1984).

2/ From 194,650 in 1967, the number of mentally retarded persons living in public residential facilities declined to about 119, 335 in 1982. Lakin, Krantz etal., "One Hundred Years of Data on Populations of Public Residential Facilities for Mentally Retarded People," 87 American Journal of Mental Deficiency (1982).

there are circumstances in which an institution is less restrictive than a group home:

> "But how do we determine 'restrictiveness'? It may be naive to assume that the most 'normative' setting is necessarily the least restrictive for everyone. What feels restrictive to one person may feel unconstraining to another. A wheelchair is a restriction to an ambulatory person, but it provides increased freedom to a paraplegic. The problem is especially complicated for persons suffering sensory or cognitive impairment. A setting which provides freedom to a non-handicapped person may be more restrictive to a handicapped person than a specially designed prosthetic environment. And the problem is more complicated still when the least restrictive alternative test is applied to the larger social environment in which a retarded person lives as opposed to facilities designed for specific programs. A small group home nestled in a hostile neighborhood, even if honorifically labeled as 'community care,' or a place 'in the community,' may be considerably more restrictive to its residents than a small village-type facility in which retarded residents are full participants in their own 'community,' even if some might call that community an 'institution.' The ultimate complexity of the least restrictive alternative analysis, however, may be that restrictiveness and freedom are experiences of individuals, and that categorical determinations of these matters will always be clumsy."1/

Writing of her institutionalized son, Elizabeth M. Boggs, a former president of the National Association for Retarded Citizens, has noted:

> "But what of the community environment? The 'community' surrounding David's 'home' is the campus of the state school. It is an ergonomic community; that is, one which has been planned to suit the inhabitants. Its swimming pool is designed so that any one can stand up in any part of it. There is a twenty-mile hour speed limit on all its roads. Its doctors make house calls. Its respite care arrangements are always available, that is, when the parent surrogate has an emergency, another one is available. There is a restaurant where no one stares at the sloppy eaters. Nobody there thinks that it is inappropriate for a thirty-two-year-old man to use a swing on the playground by choice; it is not considered dehumanizing to let a man act like a child if he wants to. David is not restricted by any such environmental taboos."

1/ Roos, "The Law and Mentally Retarded People: An Uncertain Future," 31 Stanford Law Rev. 613, 622 (1979). (underlining provided)

> From his point of view this community is more facilitative and more enhancing than the town half a mile down the road."1/

What is important to observe about these comments is that there is no preordained form of living arrangement that is best for all retarded persons. Smaller does not necessarily mean better:

> "It has been assumed that, almost by definition, quality of care for retarded individuals is superior in small institutions to that in large central institutions. Unfortunately, there seems to be little empirical basis for this assumption."2/

Both residential institutions and group homes have advantages and disadvantages both in general and in the particular. While some institutions are better than some group homes, the converse is also certainly true. The answer depends on the particular institution, the particular group home and the needs of the particular retarded individual.

It is important to note that not all persons may benefit from living in group homes and the welfare of many may actually require the specialized resources and protection of a residential institution.3/ This is especially true of the multiply handicapped and those with medical problems who require an adequate medical setting in which nurses and doctors familiar with the needs of the handicapped are at hand. Parents of these children

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1/ Boggs, "Who is Putting Whose Head in the Sand Or in the Clouds as the Case May be" in Turnbull & Turnbull, Parents Speak Out 63 (1978) (underlining supplied)

2/ Balla, "Relationship of Institution Size to Quality of Care," 81 American Journal of Mental Deficiency 117 (1976).

3/ "Small residences with half a dozen clients may be unable to provide specialized care and could isolate the severely retarded person more fully than life in a larger institution***." Rose-Ackerman, "Mental Retardation and society: The Ethics and Politics of Normalization," Ethics 81, 90 (Oct. 1982). (underlining provided) are only too aware of the problems of finding doctors and other specialists in the community who are knowledgeable and willing to assist in the specialized care and problems of the severely and profoundly handicapped. Attempting to get a house call for an ill non-ambulatory retarded person or, conversely, attempting to transport him to a doctor's office can be a frustrating and even tragic event.

Severely and profoundly retarded persons with multiple handicaps and medical problems are not the only persons who may require the specialized resources of an institution. Those persons afflicted with behavioral disorders may also require the shelter of an institution.[1] That these persons are not insignificant in number can be noted from the concern of professionals in regard to the increasing number of readmissions of persons to residential institutions after an attempt by them to reside in the community:

> "Although there has been a steady decline in the number of new admissions to public residential facilities since 1965, there has also been an increase in the number of readmissions*** In 1964, the ratio of annual total readmissions to the average population of public residential facilities was 1:113.6. In 1969, this same ratio was 1:65.4 ***; in 1977, 1:27.0; and in 1980, 1:25.6 ***"[2]

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[1] "The finding of more frequent affective behaviors among those in jeopardy of placement failure suggest that group homes may be less tolerant of, or capable of dealing with problems stemming from chronic characterological traits (affective behavior problems) than with episodic behavior problems."
Jacobson and Schwartz, "Personal and Service Characteristics Affecting Group Home Placement Success," 21 Mental Retardation 1, 5 (February 1983).

[2] Lakin, et.al, "New Admissions and Readmissions to a National Sample of Public Residential Facilities," 88 American Journal of Mental Deficiency 12 (July 1983) (underlining supplied)

(2) Detailed standards of care and inspection should be made a part of any bill that seeks to obtain increased federal funding of community facilities.

One grave deficiency of S. 2053 is that it is almost devoid of any statutory standards to which group homes would be held in the kind of care that they would be required to provide to their retarded residents. The closest that the bill comes to setting standards are provisions that would require States to enter into agreements concerning group homes:

(i) to assure that each resident has some sort of "written plans of assistance" (Section 1918(h)(2)(D)) and of "medical assistance" (Section 1918(I)(i) and

(ii) to meet "such standards of safety and sanitation" as are established by the Secretary of Health and Human Resources and state law (Section 1918(h)(2)(E)(i)).[1]

To put this regrettable absence of real standards of care in proper perspective, it is necessary to compare the experience of the retarded in residential institutions.

There was a time when institutions operated in a relative vacuum without the framework of clear standards of care. With a lack of adequate funding and minimal staff, inhumane abuses became rife. Eventually, in the historic case of Wyatt v. Stickney, 344 F. Supp. 387 (1972), a court elaborated a set of express minimum standards of care that an institution was required to meet. The order of the court covered thirteen pages of explicit standards.

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[1] In addition, the bill would require agreement to provisions that would "ensure continuity of medical assistance for severely disabled persons who reside in a facility or institution that ceases to provide such assistance" (Section 1918(i)(1)(B)). This is limited in its scope to an institution or facility that once provided medical care to an individual but then discontinued it.

> "The decree set forth standards guaranteeing basic patient rights to privacy, presumption of competency, communication with outsiders, compensation for labor, freedom from unnecessary medication or restraint, and freedom from treatment or experimentation without informed consent. Requirements were established governing staff-to-patient ratios, educational opportunities, floor space, sanitary facilities and nutrition. The court also ordered that individual treatment plans be developed, that written medication and restraint orders be filed, and that these be periodically reviewed."1/

Among the most important provisions in the court order were minimum staffing ratios based on those adopted by the American Psychiatric Association which are reproduced below:

	Mild	Moderate	Severe/ Profound
"Unit	60	60	60
(1) Psychologists	1:60	1:60	1:60
(2) Social Workers	1:60	1:60	1:60
(3) Special Educators (shall include an equal number of master's degree and bachelor's degree holders in special education)	1:15	1:10	1:30
(4) Vocational Therapists	1:60	1:60	1:60
(5) Recreational Therapists (shall be master's degree graduates from an accredited program)	1:60	1:60	1:60
(6) Occupational Therapists	--	--	1:60
(7) Registered Nurses	1:60	1:60	1:12
(8) Resident Care Workers	1:2.5	1:1.25	1:1

The following professional staff shall be fulltime employees of the institution who shall not be assigned to a single unit but who shall be available to meet the needs of any resident of the institution:

Physicians	1:200
Physical Therapists	1:100
Speech & Hearing Therapists	1:100
Dentists	1:200
Social Workers (shall be principally involved in the placement of residents in the community and shall include bachelor's degree graduates from an accredited program in social work)	1:80
Chaplains	1:200"

1/ "Wyatt v. Stickney and the Right To Treatment," 86 Harvard Law Review 1282 (1973).

Subsequent to the Wyatt case, the federal government adopted a somewhat watered down but detailed set of minimum standards by way of regulation for public residential institutions for the mentally retarded which qualify for medicaid assistance. These are set forth in 42 C.F.R. Section 442.400-442.516. The standards apply to the civil rights of the residents, communication between them and their families, health and safety, records, transfers to other facilities, activities, personal possessions, discipline, physical, chemical and mechanical restraint, behavior modification, hygiene, grooming, grouping of residents, location, size and furnishing of bedrooms, bathrooms and dining rooms, heating and ventilation, dental service, food and diet requirements, medical, nursing and pharmacy services, as well as therapy, social, psychological and speech and audiology services.

Standards such as those that were adopted by the Wyatt court and those that appear in the federal regulations are absolutely essential to assure the well-being of retarded persons. Without them, care deteriorates into neglect and then into outright abuse. It is no answer that group homes will be different from institutions because they are small or because they are located in the community or because they may have devoted employees. Unless they are subject from the outset to rigid standards, they will deteriorate, too. This is the lesson that California has recently learned after a special state commission studied conditions in its community care facilities.

After extensive investigations of the 22,000 community residential care facilities in that State (of which 18,000 were licensed for six or fewer residents) the California Commission stated:

> "The first finding of this study is the most shocking: California is tolerating the operation of numerous community care facilities in deplorable conditions. The residents are subjected to physical and sexual abuse, neglect, and generally unsafe living conditions. As one representative of the community care industry observed, 'the conditions are far more severe than ever existed in nursing homes fifteen years ago. It's a snake pit out there.'
>
> The unfortunate difference is that few people, particularly government officials, are aware of the unconscionable conditions which thousands of community care residents, most of whom cannot care for themselves, must live in each day.
>
> Members of the Little Hoover Commission visited facilities and saw first-hand the dirt, the neglect, and the emptiness."1/

Proponents of S. 2053 may suggest that it would be cumbersome and awkward to incorporate standards of care for community facilities into a statute and that these should rather be left for the courts or the administrative agencies to develop.2/ This is merely postponing consideration of what should be the most important matter of any bill that would extend community facilities. If there is a fear that the standards, once established by statute, will become entrenched, so much the better. They may be expressed as minimum standards that an administrative agency may tighten (but not loosen) as conditions indicate the appropriateness of such action.

Are minimum standards ever incorporated into a statute? Of course. In fact, the U.S. Supreme Court noted that the Senate version of the bill

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1/ Commission on California State Government Organization and Economy, "Community Residential Care in California," at p. 1 (Dec. 1983) (hereafter referred to as "California Report")

2/ See, e.g. Gilhool, "The Uses of Courts and Lawyers," Changing Patterns in Residential Services for the Mentally Retarded 155, 170 (1976).

which subsequently became the Developmentally Disabled Assistance and Bill of Rights Act:

> "***contained over 400 pages of detailed standards 'designed to assist in the protection of the human rights guaranteed under the Constitution.' S. Rep. No. 94-160, p. 34 (1975)."[1]
> (underlining provided)

Those who have the welfare of the retarded at heart should insist upon the inclusion of standards of care in the bill from the outset.

(3) Real means of enforcement of standards of care that would be set out in an amended bill would have to be afforded, on behalf of the retarded, to both the supervisory agencies and the families of the retarded.

A look at the enforcement provisions of S. 2053 shows them to be sadly deficient. At most they seem to be but three vague and feeble provisions:

(i) Section 1918(f) provides that the Secretary may treat certain payments made to a state as inappropriate;

(ii) Section 4 confines itself to reduction of certain funds if residential institutions (but not community facilities) do not meet federal standards for them;

(iii) Section 5 allows individuals to bring suit against a State plan, but apparently not against a community facility which is in violation of whatever vague standards may be found or deduced from the bill.

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[1] Pennhurst State School and Hospital v. Halderman, 101 S.Ct. 1531 at p. 1541 (1981). These standards were unfortunately lost when the House bill was substituted in conference. See 2 U.S. Code Congressional and Administrative News 961 (1975) at which the House Conference Report No. 94-473 noted:

> "The Senate amendment, but not the House bill states the purpose of the bill of rights to be establishing standards to assure the humane care, treatment, habilitation and protection of mentally retarded and other developmentally disabled individuals who are served by residential and community facilities and agencies."

The absence of real enforcement measures in the bill practically guarantees that abuses in community facilities, if detected at all, will go unchecked indefinitely.

Instead of creating a system of federally financed community facilities with built in enforcement problems, would it not make more sense to explore realistic remedies? In the related area of nursing homes similar problems have been uncovered:

> "If HEW's performance in enforcing standards has been ambivalent, the efforts of many states have been aptly described as 'a national farce.' The enforcement pattern is all too familiar: (1) the inspection force is understaffed; (2) inspections are infrequent; (3) advance notice of the inspection is routinely sent to the facility; (4) inspections are cursory and ritualistic; (5) they concentrate on the physical plant rather than patient care; and (6) adverse recommendations are ignored."[1]

Professor Regan has addressed some of these problems with the following suggestions for a workable system of inspection and enforcement. In such a system:

> "1. Complaints against a facility, triggering the inspection-citation system, may be filed by any person, not just the state agency.
>
> 2. No advance notice of an inspection should be given unless authorized by an administrator of the agency or otherwise required by law. Public employees giving advance notice in violation of law should be subject to disciplinary action.
>
> 3. The complainant or his representative may be allowed to accompany the inspector on his tour of the facility.
>
> 4. At least two classes of citations should be established, depending on the degree of risk of death or serious physical harm that can result from the violation. Different penalties would be attached to each class of citation.
>
> 5. Each citation which has become final must be posted in a place or places for a specified period in plain view of the patients, persons visiting those patients, and persons who inquire about placement in the facility.

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[1] Regan, "Quality Assurance Systems in Nursing Homes," 53 Journal of Urban Law 153, 185 (1975).

> 6. A report listing all***homes and the status of any citation issued against them should be published periodically and made available to the public.
>
> 7. All records pertaining to the citation should be open to public inspection.
>
> 8. Retaliation against any patient or employee who participates in the citation process should be prohibited.
>
> ***"[1]

Those recommendations should be made a part of a system of inspection and enforcement of group homes. They should be incorporated into any bill which conditions the increased availability of federal assistance to states for group homes. Moreover such procedures should be required to be in place before federal funds are made available for this purpose.

The California Commission which disclosed the glaring deficiencies of community facilities in that state also made a series of recommendations to put teeth into the law which are worth noting. Among other things, it recommended the following:

(i) the development of "***specific criteria regarding abusive or life-threatening conditions in a community care facility that indicate when***[the supervisory authority] should seek a temporary suspension order with the intention of revoking the license."[2] The Commission further recommended the establishment of "***an emergency fund, possibly out of increased fines***to provide for the relocation and care of residents when***[the supervisory agency] closes facilities on short notice."[3]

(ii) Increased fines for violations. The Commission stated:

> "If fines are to deter willful violations of law and regulations, they must be high enough to make noncompliance a financial hardship for the administrator."[4]

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[1] *Id.* at pp. 193-194.
[2] California Report at p. 93.
[3] *Id.* at p. 94.
[4] *Id.* at p. 96.

> "We further recommend that fines for repeat violations be trebled."[1]

> "We recommend that***[the supervisory authority] retain in its own budget 50 percent of the total fines revenue to support enforcement activities; we further recommend that the remaining 50 percent be used to support monitoring efforts by volunteers."[2]

(iii) Require all licensees of community facilities to be bonded. The Commission stated:

> "We recommend that***all community care licenses***be bonded***."

> "[The supervisory agency]***will have the right to collect the fines from the bonding entity. When the amount owed for fines exceeds the amount of the bond, we recommend that***[the supervisory agency be required] 'to automatically initiate license revocation proceedings."[3]

(iv) Authorize the supervisory agency to place a community care facility into receivership. This should

> "***include a wide choice of receivers; a mechanism whereby residents can request, or petition for, receivership; and wide discretion to invoke receivership and determine the duration of receivership in any given situation."[4]

(v) Authorize the supervisory agency to develop a "crisis team that could be sent to facilities that are experiencing administrative failures, but which [it]***considers redeemable."[5]

(vi) Private actions. The Commission recommended:

> "Encourage Private Action Against Unsatisfactory Community Care Facilities by Allowing Recovery of Legal Fees by Attachments of Administrators' Property."[6]

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[1] *Id.* at p. 97.
[2] *Ibid.*
[3] *Id.* at p. 98.
[4] *Id.* at p. 99.
[5] *Id.* at p. 99.
[6] *Id.* at p. 100.

In our view, effective means of enforcement such as those set out above should be required in any bill that would increase federal aid[1] to states in respect of group facilities. Only with these in place can we rest assured that the welfare of the retarded will be safeguarded. We believe these safeguards are necessary because the nature of a decentralized system of small group homes, uncoordinated and without the layers of supervision that exist in institutions, will otherwise lead to a silent corrosion of care and responsibillity. In the words of Professor Etzioni:

> "'Small'***means even more difficult to oversee, inspect, and keep tabs on, than big, and hence even more unresponsive to reform."[2]

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[1] Authority already exists for states to receive federal funding for community facilities. Under current law the Secretary of Health and Human Services may approve waiver requests submitted by states that wish to provide medicaid-reimbursable home and community based services to the mentally retarded. See Section 1915(c)(1) of the Social Security Act, 42 U.S.C §1396n(c). In order for such a waiver to be granted, a state must provide assurances, among other things, that "***necessary safeguards (including adequate standards for provider participation) have been taken to protect the health and welfare of individuals provided services under the waiver and to assure financial accountability for funds expended with respect to such services***." As of December 1983, 31 states had submitted a total of 48 such requests to the Secretary which expressly sought authority to provide home and community care services for the mentally retarded and developmentally handicapped. Twenty-nine of these requests have been approved, three disapproved and one rejected as of that date. See National Association of State Mental Retardation Program Directors, Inc., Position Statement on S. 2053 at p. 15 (Feb. 1984).

[2] Etzioni, "Deinstitutionalization...A Vastly Oversold Good Idea," Columbia 14, 17 (Spring 1978).

WRITTEN TESTIMONY ON SENATE BILL 2053- COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983

Submitted by

The Parents Association
Hammond State School
Route 3, Box 165 P
Hammond, LA.

March 5, 1984

Note: Request to give verbal testimony at Feb.27,1984 hearing was not granted. This written statement is submitted for the record in accorddnce with normal procedure in such cases.

The Hammond State School

With its 687 residents, this "awful" institution would seemingly be fair game for the anti-institutionalists, many of whom seem to be obsessed with the matter of size. Isn't this a place with bars on the windows and children lying neglected in crowded wards? The answer is a resounding "No". The fact is that a devoted staff and an active Parents Association have joined together to make the school's environment as close as possible to a home-like atmosphere. While we feel that HSS is outstanding, we know that other large institutions across the country -both public and private - are doing a fine job. We are sure that they can and will speak for themselves.

Because "institutions"have been unjustly maligned, we will devote part of this testimony to describe the character of HSS. The school is located about 60 miles outside New Orleans on 100 beautiful woodland acres donated by a private citizen. It enjoys an excellent reputation, thanks to sound, compassionate management, the cooperation of the Parents Association, and a modern physical plant.

The first residential center for Vocational Rehabilitation residents was the Seid Hendrix Memorial Center established at Hammond State School in 1964. This center offers evaluation and work adjustment training to young men and women housed there.

About ten years ago, HSS began preparing for accreditation under the Title XIX Program as an Intermediate Care Facility for the mentally retarded This included renovation of the school's cottages at a cost of $3.5 million, and completion of a new Section of Total Care. Accreditation was awarded and is being continuted in strict compliance with stringent governmental standards. The cottages are so architecturally arranged as to enable the severely and profoundly retarded persons to live their lives as fully and as independently as possible.

HSS is the official domicile of the Louisiana Special Olympics, housing the Special Olympics staff. The school, active in this area for several years, was partially responsible for the International Games being held at Louisiana State University in Baton Rouge in 1983. Participants came from every state in the United States, five U.S. Territories, and forty seven foreign countries.

The school is presently in the process of doing a self-study with the goal of becoming accredited by the Accreditation Council on Mentally Retarded and Developmentally Disabilities (ACMRDD). This is being done in cooperation with the Parent Association, which is represented on the committee conducting the study.

HSS was the first facility for the mentally retarded in the country to form a JAYCEE Chapter. The Chapter has won numerous awards for community work and other activities. The school asked for and was granted special dispensation from the National Office to have a Jayne Chapter. This was done even though the National Bylaw s require a Jayne being married to a JAYCEE.The Jayne Chapter is also very active.

The school's Music Therapy Group has appeared on innumerable radio and television programs. They have been guests on television stations in New Orleans, and have made numerous appearances on the Dwane Graham "Morning in Louisiana" Show, Channel 9, Baton Rouge, La. They are in constant demand by many civic organizations, church groups, Louisiana Conference of Social Welfare and by ARC groups, AMMD Meetings, and have performed for the Governor at the State Capital. A highlight was a visit to Washington,D.C.,when they entertained the President in the White House.

The school's budget has grown from less than $1 million to the present budget of approximately $20 million. This reflects the steady increases in services which today finds HSS with a full spectrum of activities benefiting the retarded. The school is considered the Epilepsy Center of the State and the only tracheotomy and gastrostomy unit in Louisiana, housing some 40 residents.

Over the years, the Parents Association has worked very closely with HSS officials to provide the best possible living environment for the residents. Contributions included $67,000 toward construction of an all faith chapel, construction on gazebos throughout the campus, financing of an annual Bible School, sponsorship of Christmas parties and parades, purchases of wheelchairs, televisions and other appliances, providing materials and furnishings for both the gymnasium and swimming pool, subsidization of the Industrial Therapy Program and numerous other activities. (A partial list is attached).

Residents are regularly entertained through picnics, trips to State Fairs, football and other athletic contests, and various other outings. A group of "Foster Grandparents" visit the school several times each week to spend time with the residents. The school also has a Parent-Surrogate Program with parents "adopting"children other than their own, whose parents have expired. The participants visit regularly with the children, giving them Christmas and Birthday presents, and otherwise envoking a feeling of family among them.

Residents of Hammond State School

Level	No.	Percent
Profound	430	62.6
Severe	114	16.6
Moderate	82	11.9
Mild	45	6.6
Borderline	16	2.3
	totals 687	100.0

A total of 265 residents, or 38.6% are non-ambulatory. Four hundred or 58% are non-verbal. Those without self-help skills total 275 or 40%. Of course, there are overlappings, with some having more than one disability(e.g. blindness, deafness).

It is difficult indeed to imagine that the majority of these residents could function in a community setting, without the 24 hour attention that they require. Many would be easy prey for murderers and rapists and would be in constant peril from things normally considered as routine, such as crossing a busy street unattended. Some would suffer the fate of being a virtual prisoner behind locked doors and windows. (A neighbor of a community home recently noted that since the home opened seven months ago, no one has seen the residents.)

It would be wonderful if these people could be mainstreamed and striving for this goal would be admirable if such a goal were attainable. But the truth is they would be utterly lost in a community setting. It is wrong to stereotype the retarded. There are different degrees of retardation and what will work for one will not work for another.

The Obsession with Size

S.2053 provides that Community and Family living facilities will not exceed three times the average household size in the areas in which they are located. According to the National ARC, census figures would therefore limit the size of these residences to 9 or 10 people. (Units now having up to 15 residents would be "grandfathered"in). In the process of setting up such homes for all retarded citizens, Title XIX funds would be diverted from units with more than 15 residents, thus eliminating the many excellent large scale State and private schools throughout the country which are providing a service for the severely and profoundly retarded that could by no stretch of the imagination be duplicated or even approached by small community living units.

Proponents of S.2053 seem to be obsessed with the idea that units of more than 15 residents are, per se, verboten. This highly arbitrary concept flies in the face of numerous studies to the contrary. But formal studies aside, it should be obvious that large is not necessarily bad, just as small is not necessarily good.

Size of a facility is not as important as other factors such as the nature of social groupings. In larger institutions, the residents engage in a more social behavior,particularly with peers and are more likely to have intense reciprocal friendships than in smaller facilities

The Cost Factor

A common contention of the anti-institutional group is that institutional care is far more costly than community-based residence care. Little in the form of documentation has been offered in support of this position. What data has been presented is obsolete: moreover, the instiutional costs reported inevitably include the full spectrum of services offered by large institutions, while reflecting for the small units only the cost of housing, food and live-in staff. This is comparing apples with oranges.

Despite this obvious distortion, some studies have shown that institutional costs are still lower than those for small homes. Given the Economy of Scale principle, large units should have lower unit costs, a factor commonly overlooked by those who would insist that S.2053 would save money.

The fact is that no reliable cost data is now available. Perhaps in any event cost should not be a primary issue in providing services to retarded people. But if it is to be considered, a complete objective study should be made by an independent group, giving full consideration to the kinds of services available at both types of living arrangments, and the number of cost units to which overall expenses can be spread.

Community - Based Residences

We are fully in favor of properly staffed and operated homes for those retarded persons who would indeed function better in such homes than in large-scale instiutions. As parents, we dearly wish our children could fit into these homes, but from long and painful experience, we know that this just cannot be. (If it could, we would have our children in our own homes!).

We often hear of the abominable state of some community-based residences. Some are extremely unstable, closing abruptly without any consideration of or provision for the residents. What results are forced transfers, which can be very unsettling to the persons involved. Proper training is often lacking, and personnel turnover can be staggering. If all this can have a detrimental effect on the moderately retarded person who might ordinarily fit in with a properly operated home, imagine what this would do to the severely and profoundly retarded persons. One authority found that the most dramatic and tragic consequence of the inability of profoundly retarded people to adjust to even a single relocation from institution to community living was an increased incidence of death. The National Association and other proponents of S.2053 should realize this and abstain from promoting a program which would experiment with sociological ideas rather than face reality.

Efforts to locate community homes are constantly being stymied by neighborhood groups who unfortunately, for various reasons, feel that the presence of retarded persons would somehow adversely affect their property. One could possibly be supportive of their position, if severely and profoundly retarded lived in their neighborhoods, not because these unfortunate people would do anyone any harm but because they would be in constant danger of wandering off, getting lost, and possibly being injured or killed. Regardless of the reasons for and the morality of the neighbors' position, their stand represents a real and continuing restraint on the location of these homes in suitable neighborhoods.

Commercial interests are now offering community homes. One could argue that one concern operating several homes could through experience become more proficient, but what will happen if a venture turns out to be a money-losing proposition? Obviously it would be terminated, with the residents being subjected to the trauma that goes with transfers. The profit motive could encourage an operator to curtail services to the detriment of the residents.

In this litiguous age, lawsuits involving defective care of the severe and profoundly retarded would be rife. Government agencies as well as community homes would be targets.

Implimentation of S. 2053 would be an administrative nightmare.

Rights of the Severely and Profoundly Retarded

Retarded citizens are entitled to all citizenship rights,and in particular. to the freedom of choice of residential facilities that best suit their particular needs. Proponents of S.2053 will point out that many former institutional residents expressed a preference for community living. The fact that they could respond to a systematic interview would indicate that these persons were functioning at a reasonably high level and no doubt did not belong in a large multi-purpose facility in the first place. Compare this situation with one involving the severely retarded, many of whom cannot talk.

Just as many of the moderately retarded belong in small homes, practically all of the severly and profoundly retarded belong in an environment that will best suit their needs. And this is an environment with 24 hour availability of medical and nursing services and the sophisticated equipment and other facilities that go with these things.

At the national ARC convention in Detroit, a panel of retarded persons were featured, all of whom spoke highly of community-based homes. These articulate people made splendid presentations. Proponents of S.2053 had a retarded person testify in favor of the legislation at the Senate hearing on February 27,1984, and this person also did an excellent job. In both instances, the speakers were no doubt thriving in their community settings, with some possibly gainfully employed. We applaud this, and repeat that we are strongly in favor of properly run homes for the moderately retarded. We only wish that all retarded people could do as well in these homes, but we know that the severely and profoundly retarded cannot.

Position of National ARC does not reflect that of all ARC Chapters

In advocating S.2053, the national ARC wrongly implied that the state ARC chapters also endorsed the legislation. The fact is that the states voted only to support the rights of the retarded to live in community settings. The national group does not speak for all state chapters, and certainly not for the parents of the severely and profoundly retarded children who know from sad experience that they could not function in small community-living units

At the recent ARC national convention in Detroit,several states ARC representatives vehemently protested the national group's endorsement.with some warning that such . unilaterlal actions could split the ARC.

Community placement will not lead to improvements in functional levels

There is no clear evidence to support the relative superiortiy of community placement,particularly for the types of severely handicapped residents who constitute the bulk of the current instiutional populations, despite assumption to the contrary reflected in the proposed legislation.

The role of parents

Throughout history of the anti-institution movement, little if any input has been asked of the parents of severely retarded children. This type of approach is usually taken by those "professionals" who discount the opinions and feelings of parents, relying on their academic training that often leaves little room for judgements based on the gut experiences of parents. But to ignore parents and to write them off as not being emotionally conditioned to know what is really best for their own flesh and blood is not only unfair, but rather foolish. It may come as a surprise to some that the parents know more about their children than the professionals do, especially those experts who may have spent only a few minutes or no time at all with the children.

One good thing that has come out of the anti-institution movement and its climax in the drafting of S.2053, is that the parents are now alerted as to what is going on, and their presence is at last being felt. Parents Network and other groups are in the midst of programs informing the parents and educating those well--meaning people who do not have retarded children and are therefore not aware of the need for institutions that, noble though it may sound, the concept that _all_ retarded persons should be in community homes is wholly unrealistic. The parents are also letting Washington know where they stand.

Summary and Conclusions

We are strongly opposed to Senate Bill 2053 for the following reasons:

1. It would divert Title XIX funds from large-scale institutions to small community-living units, resulting in the closure of the former. Large scale schools -state and private -will always be needed for the severely and profoundly retarded who require 24 hour attention and the ready availability of medical and nursing care with the sophisticated equipment that goes with these things. Large and small units are not mutually exclusive. Both are

needed. One cannot stereotype the retarded which S.2053 tends to do. There are different degrees of retardation, and what will work for one will not work for another. And being big is not necessarily bad, just as being small is not necessarily good.

2. There is substantial opposition to S.2053. This comes from State ARC chapters, and, more importantly, from parents of retarded children.

3. There is no question that some retarded persons can function well in small homes, and sufficient funds should be made available so that all persons in this category are given the opportunity of living in properly operated community homes. But to apply this premise across the board is sheer lunacy. It should be obvious that if a severely retarded person could fit in with a community living situation, his parents would have him in their own home.

4. We maintain that an independent, thoroughly objective cost study would reveal that per-diem costs of small homes would be highter than instiution costs. Those holding the opposite position use stale data which ignores the Economy of Scale principle, and compares costs of a continuum of service available at large institutions with simple room and board costs of community homes. What the proponents come up with is definitely slanted against institutions.

5. The instability of community homes and the traumatic effect reassigment would have on retarded persons as homes abruptly go out of business. Attitude of neighborhood groups opposing location on

homes in their areas is already creating problems in locating retarded persons, with the liklihood that the solution will lie in opening these homes in less desirable areas.

6. It would be highly arbitrary to dismantle schools which over the years have evolved into fine instiutions simply to test the idea of a relatively small group that institutions, per se, are bad and that small community homes will be the answer to everything.

7. The national ARC and other groups wishing to mainstream all retarded citizens, and ourselves really have a common goal: we want the best for these citizens. It is indeed unfortunate that we are involved in a large vs. small dichotomy. There really is need for both types of environment. It is our hope that both factions can unite in a program that will indeed benefit the retarded citizens, including those that are severely and profoundly retarded.

Submitted by:

Parents Association

Hammond State School

The following are some of the accomplishments of the Parents Association since it was organized at the end of 1964.

Our first project, financing a brightly painted, wooden fence for a playground area, used by the smaller, ambulatory children. This has since been relocated and replaced with a more durable metal fence.

The next major undertaking was buying the colorful tractor train and coaches, that still give so much pleasure to the residents, as they ride around the grounds and in various parades in the sourrounding areas.

Through the years many different types of picnic tables and benches have been purchased and placed around the grounds for the convenience of the residents and their visitors.

Funds were supplied for the finishing materials and furnishings for both the Gymnasium and Swimming Pool.

Needed materials were purchased to build the boat pavilion, near the gymnasium.

To protect the residents and their visitors, from sun and rain, funds were given to build the gazebos, that dot our compound.

The Industrial Therapy program was able to be started because of our ability to subsidize this activity.

Much needed linens were supplied, during some of the past linen shortages.

Our All Faiths Chapel Building Fund raised $67,000.00 in addition to the $100,000.00 that Mr. Billups contributed. This enabled us to build and completely furnish our Chapel and offices, in a matter of four years.

Our annual vacation Bible school, organized by Brother T. V. Owen, is financed from the Chapel Fund.

Since building the Chapel we have improved the outside by creating a beautiful little patio between the Chaplain's offices and the Prayer Room. We also changed the lighting system and now have a much brighter and prettier interior. Safety glass was installed and a complete sound system that can be used in and out of the building was purchased.

The Chapel Fund has paid the cost of fencing in our Cemetery, erecting a lovely wrought iron entrance with the school's name and also build a beautiful, granite monument, in honor of those residents who are buried there.

Christmas is beautiful at the school. This is a time of great activity for the children, staff, parents and friends. A Christmas parade is organized and travels the whole campus so that all residents can view and enjoy the event. Christmas parties are held in all areas with 22 Santa Clauses the center attraction. Christmas morning all residents who are unable to be at home, receive a special gift. The staff members are also remembered with a small Christmas momento. This program has become such a tradition that all the residents look forward from one year to the next for this season.

Through the years we have supplied such needed items as washers, dryers, air-conditioners, T. V.'s, electric fans, wheelchairs, electric shavers, a kiln for ceramics, C. B. radios and a special lawn mower for the play areas.

We have been able to underwrite the publication of the Choir's first album and also generously contributed to their Washington trip.

Every year we financially assist in the Easter Program.

We have added to and accumulated funds to provide two Station Wagons and a Compact car for the Social Service Department. These are used to transport our residents to the various parts of town that require transportation.

We established a visual record of our past superintendents. Pictures of Mr. E. Roy Rogillio and Mr. Edgar Lee Morgan, were made from small photos and installed in the lobby of the school.

✓ Our Legislative Committee keeps in close contact with our State and Federal Legislators. They have been able to insure that the school would not be without natural gas during the energy crises. They were instrimental in having the school's budget increased, when more direct care was needed for the children. They also petitioned the Governor for his aid in securing housing and financial help to obtain the necessary medical personnel that was needed. Our political involvement is a most important activity that requires the support of all our parents and friends.

We are constantly trying to make the public aware of the Hammond State School and educate them to the needs of our children.

We have created a special fund to furnish a "Works Activity" building that the State has built for the school.

Seven pianos were bought to be able to have them in all areas, so that the residents could be entertained with music and song.

We have paid to have a train room built to house a complete collection of electric trains, that was given for the enjoyment of the residents. This collection will cover an area of 64 square feet.

An area for outdoor picnics, has been developed, this means shelters, tables, benches, barbecue pits and water facilities. This we feel is important as it will provide a space where private gatherings can be had, right on the school grounds.

A very generous contribution was given to the "Walk Down Highway 1" promotion to raise funds for the International Special Olympics.

In answer to an emergency plea from our Superintendent, funds were made available to purchase an auto clave cart to complete the unit provided by the state.

Many problems and needs within the Hammond State School have been solved by the Parents Association and the School, working closely together, for the benefit of the residents. This is the reason for our Association, first for the good of the children, their welfare and protection, secondly to aid the school, our parents and guardians.

Concerned Families
of Hazelwood Facility

Mr. Chairman and members of the Health sub-committee. My name is Louise Underwood and I represent over 1000 caring and concerned families of the mentally retarded from the state of Kentucky. These families are well satisfied with the care our children and relatives receive in our fine state and private residential institutions for the mentally retarded. If I may, I'd like to give you the results of our experiences with institutional care and community care in Kentucky over the past 10 years.

As one of the leading states in developing community services for the mentally retarded in the early 1970's, Kentucky started a program called the "Circle of Care". The purpose of the program was to place MR children back into communities under the supervision of Regional Comprehensive Care Centers. At face value the program appeared to be a good one but after operating about three years it was abandoned. Poor monitoring, excessive cost, and self interest resulted in inadequate care, neglect and even death for some of our helpless MR children. Some are alive today because they were fortunate enough to be returned to the safety of our state residential facilities.

In 1975, Kentucky began another well-meaning deinstitutionalization effort called the "New Directions Program". Again, millions and millions of dollars were poured into another program designed to care for the mentally retarded in the community. This time the state's child welfare department's social workers were plugged into the system to assist the comprehensive care centers social workers in monitoring placements after the children left the state institutions. The program looked great on paper! Part of the program involved placing profoundly retarded, nonambulatory children into the very-best community skilled nursing facilities. However, before long problems began to develop. Monitoring by inexperienced social workers, conflict between agencies, improper or inadequate placements and increasing cost all began to lead to neglect and rapid movement from one type of placement to another. Children became lost in the system. Our Hazelwood children who were placed into very fine community, skilled nursing facilities started to deteriorate and some began to die. One of our friends at the facility did a study and found that the life expectancy of a profoundly retarded, nonambulatory person with no self help skills and who had chronic medical problems had a life expectancy of 8.8 months after leaving Hazelwood. A similar type of child at the facility but one who was too weak to be placed into the community, had a life span of 2.3 YEARS at Hazelwood. I want to emphasize that only the healthiest and strongest left Hazelwood for community placement. Once they were in the community, their life spans were dramatically shortened. In April 1978, Roger T. (an 18 year old young man) was placed out of Hazelwood into a very good community skilled nursing facility which specialized in caring for such persons. Five days after leaving Hazelwood, he died. Roger's death and the deaths of others resulted in a suit against the state of Kentucky. Because the state agreed to halt such community placements the suit was dropped. This time it had taken the lives of some of our mentally retarded children to inform the professionals what we as parents and relatives had already known. That is---- If our children could have been adequately cared for in the community, we would have kept them at home with us in the first place!!

In 1979 Kentucky began a third deinstitutionalization effort and called it the "New Neighbors Program". Again, the state had the non-profit, comprehensive care centers playing a major role in the program. This time, however, the state's own Child Welfare social workers were not included in the after placement monitoring process. In previous deinstitutionalization efforts these state social workers had made the comprehensive care centers too uncomfortable by reporting too many problems. I should like to remind you that these community comprehensive care centers are now functionin at less than 50% capacity then when they were back in the days of plenty. Some in Kentucky have taken bankruptcies and others are fighting for their financial survival. Staff have been reduced, personnel turnovers are frequent and funding sources are becomming increasingly uncertain. In spite of all this instability, Kentucky's Division for Community Services again contracted with the Comprehensive Care Agencies and continues to use them to develop placement sites and then to do their own monitoring. It is quite believable that the Comprehensive Care Centers are not going to find fault with a program from which they financially benefit and it is conceivable that the state's Division may hesitate to criticize its own program if things don't go well. Again, the welfare of our children is exposed! This time the state social workers are not in the field to monitor what is happening to our children. Twice before, deinstitutionalization programs could not function even in times of better funding, more personnel and more resources so it is no wonder that we have again began to hear of abuse and neglect. Recently we were able to obtain a few sample reports concerning some of the children placed into community placements from state residential institutions under the New Neighbors Program. I have attached copies of these reports to materials I gave to the committee. These reports show that many of the community placements are anything but successful when you compare the care these MR persons received in our state residential institutions.

We parents and relatives of the mentally retarded in state and private institutions number over 1000 families in Kentucky. We have had extensive experiences with community placements. We know that community placements are not appropriate for all types of mentally retarded children. We know that there is a significant difference between the following:

1) A profoundly retarded child.
2) A profoundly retarded child who is non-ambulatory and who has minimal self-help skills.
3) A profoundly retarded child who is non-ambulatory and who has minimal or no self-help skills and who is further effected by chronic medical problems. Children to whom a common cold becomes life threatening pneumonia because their immunological defense systems function poorly.

Many authors of community MR programs deal with the later two catagories of MR children by omission. As an example, I am including to the committee a copy of one such program designer's definitions of various classifications of Mental Retardation. In it he completely ignores the existance of the very type of child that fills our Hazelwood facility. Such children as these make up approximately 10-15% of all mentally retarded children. Such children would die without intensive, ongoing and well-monitored care as is found in Kentucky's state residential institutions.

This type of mentally retarded child cannot be successfully placed into community settings unless tax payers are ready to spend upwards of $40,000. PER YEAR per child (just to start the placement). Attached is a copy of correspondence identifying this amount as the cost for one of Hazelwood's residents who was to be placed into the community. The cost of care for this young man was computed by Kentucky's Division for Community Services who are very eager to place children out of our fine state institutions. Knowing them as I do, I would say the figures probably fall short of the true cost of community care for this person. Since this particular resident of Hazelwood is one of our few higher functioning individuals who has no medical problems, community care very well may be appropriate for him. But----considering cost by itself---this young man has available to him at Hazelwood every conceivable type of service, therapy, medical care and teaching staff at a cost of $23,000. per year. The price for providing in the community such resources as is available to him at Hazelwood would exceed $100,000. per year if you could get it. But you can't get it in the community. How many of you know doctors, psychologist or physical therapists who make house calls? In some areas of Kentucky there is not a doctor for 50 miles and not a physical therapist for 70 or more. The Hazelwood children of whom I speak not only require ongoing preventive medical care but medical treatment that must be rapidly available if it is to be effective.

Another type of mentally retarded person poorly suited for community placement is one who has severe behavioral problems. Some mild behavior problems may be successful but I am concerned about the more severe situations. I am giving the committee copies of sample reports I obtained which show what has happened to such mentally retarded persons and to the individuals who cared for them. Imagine the actual cost of taking care of a MR person with severe behavioral problems in the community whereby sometimes one-to-one care around the clock is not sufficient.

MY POINTS OF CONCERN ARE THESE:

1- Community care is NOT less expensive than institutional care for some children. Indeed, it is far more costly than institutional care.

2- Institutional care can provide more services at a lesser cost for many children because all services are located in the same facility. This is especially true for MR children who require a higher level of care.

3- There are insufficient numbers of doctors & therapists available in all communities, to travel from home to home in order to provide good care. Even if there were, the cost would be out of sight.

4. Community care programs for the mentally retarded handled through the Comprehensive Care Centers have not been as successful as the

various Associations for Retarded Citizens' Public Relations men would have you believe. Kentucky has gone through three such efforts and spent millions of dollars with little to show in proportion to the amount it used.

5. Effective Community care programs for the Mentally Retarded must be operated directly by state agencies who are directly responsible for them. Contracting out for services, even with the best monitoring system, still adds excessive layers of administrative cost. An example: The state division for community services in Kentucky contracts with the Seven Counties Comprehensive Care Centers for community services. The comprehensive care center subcontracts with the Council for Retarded Citizens for these services. The Council then subcontracts with Community Living, Inc. who finally gets the job done. Imagine how much money is wasted through all these layers of administrative contracting. There are simply too many fingers in the pie! Community care for the mentally retarded is becomming a very large and lucrative business. It provides a solution for various organizations who are eager to maintain their financial security and expand their areas of influence------and this is not always in the best interest of the mentally retarded child.
6. It is no more correct to say that one form of care is right for all types of mentally retarded children that it is to say only one form of medication is correct for all forms of illness.
7. This is but another effort, on the part of professionals who favor deinstitutionalization, to try to close our fine state

and private institutions. We have dealt with these Associations for the Retarded for years and although their strategies change their ultimate goal remains the same. At home I have a newspaper clipping from several years ago that quotes one of the Association's officials. It boldly states:

> "in our plans there is no room for institutions, large or small".

I can assure you that this association does not speak for over 1000 families in Kentucky who want good institutional care for their children, such as we have in Kentucky.

8. If Senate Bill 2053 is approved, I can assure you the cost of care for the mentally retarded will greatly increase while the quality of care will shrink. The victims will be our children!

In closing, I should like to offer a few suggestions that might continue the same level of services and at the same time reduce the cost of such services:

A/ There are many MR persons who do not require ICF/MR level of care and who would do well in a lower level of care such as PERSONAL CARE with attached MR programming (PC/MR). Personal care is less expensive than Intermediate Care. Such a level of care could be offered both in institutions and in the community.

B/ Establish a level of care higher than the current ICF/MR level. Such a level could be called Skilled Nursing MR (SN/MR). This level would emphasize skilled nursing and medical care with programs to provide stimulation for the purpose of preventing regression. Heavy/intense training in self help skills would not be necessary here because many of these children function at less than a one year level. With permanently damaged nerves and muscles, the expectations of these children developing self help skills is remote, at best. Since intense programming and training accounts for 65 to 70% of the cost of operating an ICF/MR, a significant reduction in cost could be realized.

C/ Public law 94-142 is excellent for the handicapped and some higher functioning MR children. But for profoundly retarded children who are non-ambulatory, who have no ability to communicate, who have no self help skills, who are chronically ill and who, because of permanent brain damage, function at less than one year level and who will always be dependent--- I feel that busing such children as these to school across town on cold winter mornings is not normalization but speaks more of child abuse. Yet, we do this very thing to some 70 children at Hazelwood each day because the officials say we must do it to obey the law. Some of these children who require physical therapy inorder to stop contractures from developing, must wait to receive the therapy until their little tired bodies arrive back at Hazelwood, late in the day. The very programs these schools offer (as well as the various therapies which they do not) are all available at Hazelwood AT A FAR LESSER COST.

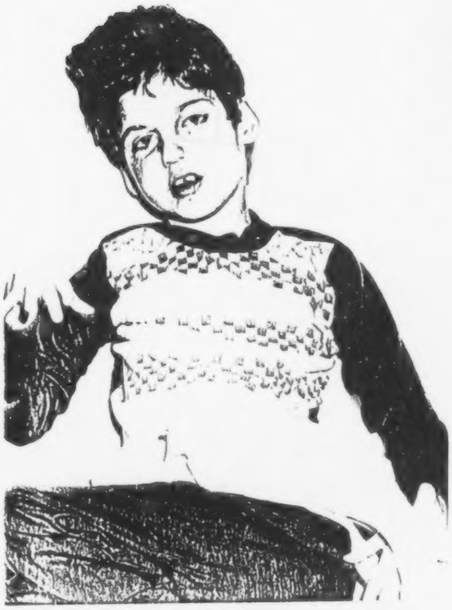
D/ Kentucky recently started providing an option for Medical Assistance to pay either for care in institutions or for care in the community. It is called Alternative Intermediate Services/Mental Retardation or AIS/MR for short. In other words, the state has just begun to financially support a system of care suited to the needs of the mentally retarded individual. Provided it does not become too costly, I believe this is the answer to the care that all of our mentally retarded children require.

I thank you for your time in letting me express the feelings of our many Kentucky families. As you know, we are people who must work for a living and must take time from work to plead the needs of our children. Since we are not endowed like the various Associations, I can say as parents and relatives of the mentally retarded, that our concerns are sincere and without any motive other than good care for our very special children.

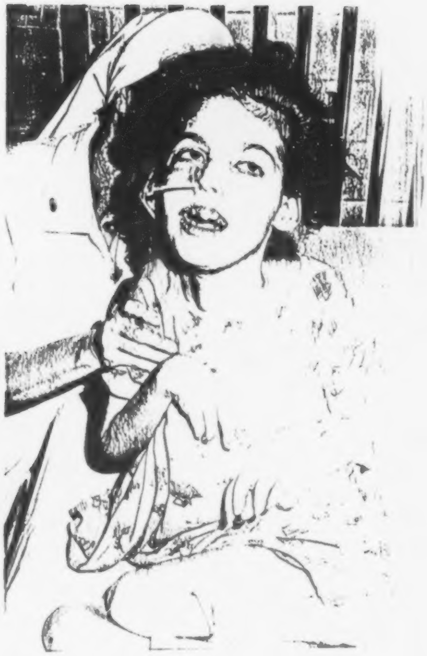
-Louise Underwood
President, Concerned Families
of Hazelwood Facility

February 27, 1984

Address: 3129 Bank St
Louisville, Ky; 40212



BEFORE LEAVING HAZELWOOD ICF/MR
FOR COMMUNITY PLACEMENT



AFTER RETURNING TO HAZELWOOD
FROM COMMUNITY PLACEMENT

COMMONWEALTH OF KENTUCKY
OFFICE FOR PUBLIC ADVOCACY
State Office Building Annex, Frankfort, Kentucky 40601

Protection and Advocacy Division
564-2967

Defense Services
Investigative Branch
564-3765

Public Defender Division
564-3754

July 25, 1983

Dr. Jeff Strully
Seven Counties Services (this is a community comprehensive care agency)
Box 628
Starks Building
Louisville, Kentucky 40202

Dear Dr. Strully:

I am a bit confused about the status of [redacted] application to the AIS/MR program. As I mentioned to you, I was told by Mr. Bill Draper that [redacted]'s estimated cost for community living has been placed at $40,000. I was later informed that a decision has, in fact, been made on [redacted] acceptance to this program. Please advise me if a decision has been made, if the cost estimate has been established, and if those seven residential slots are taken.

I understand that there may be some expensive initial costs in moving [redacted] into his own apartment. Early next week I will be receiving a report from Hazelwood ICF/MR as to what equipment belongs to [redacted] already and the purchase cost of any equipment [redacted] might need and does not own. I am also eager to work with Ms. Cassidy in identifying other resources in helping [redacted] establish himself in a new home in an inexpensive manner.

I would hope that before a final decision as to costs or acceptance is made from your agency that you would allow [redacted] time to obtain another cost estimate if deemed necessary, and to speak with you about the quality of the living situation [redacted] chooses to place himself in. I would assume that you would give his guardian and myself as his representative that same opportunity.

Note: At Hazelwood ICF/MR this person's care cost $23,000 per year as opposed to $40,000 per year plus initial cost of moving & setting up the apartment plus medical needs.

I am sure that we can work together to ensure that the procedures taken to determine his eligibility are working towards [redacted]'s benefit.

Sincerely,

Pam Clay

Pam Clay, Residential Advocate
Protection and Advocacy Division

PC/cyd

cc: [redacted]
Ms. Paula Corbett

MARCH 14, 1978

82 Residents who have been placed out of Hazelwood from 6/1/71 to 3/14/78

-5 Returned to Hazelwood after placement (did not meet criteria, etc.)

77 Permanent transfers

-1 Residents not admitted to Hazelwood for treatment but only for "holdover" until they could be sent to TIP home.

76 Residents transferred

15 died since transfer. Life span for those who died is 8.8 months (average). 20% mortality rate for placed residents.

376 Total admissions to Hazelwood

-12 Respite care cases admitted

364

-76 Transferred from Hazelwood

288 Net Hazelwood admissions

38 Died at Hazelwood. Life span for those who died is 2 years (average)

13 % mortality rate for Hazelwood Population

OF THOSE TRANSFERRED FROM HAZELWOOD:

Life span during stay at Hazelwood 2.31 years
Life span at transfer facility (nursing home) 8.8 months.

It should be noted that 14 transfers have been made within the past 8 weeks. Although these 14 have been considered in this report, such a recent concentration of placements (which is unusual) artificially decreases the mortality rate of placed residents. Prior to 8 weeks ago, placement mortality rate was 22.58%.

The 15 deaths (of residents transferred) are cases of which Hazelwood is aware. It is very probable that other deaths have occurred of which we are not aware. No surveys have been made during the past three months during which deaths of placed residents also may have occurred.

DEATHS AFTER PLACEMENT

NAME	ADM. DATE	INPATIENT YRS AT HAZELWOOD	TRANSFER DATE	YEARS OF LIFE AFTER TRANSFER	DEATH	BIRTHDATE	AGE AT DEATH
SCHRICHTE, JOAN	11/13/72	.90	10/09/73	1.06	11/01/74	05/31/29	45
MEREDITH, LOTTIE	07/10/73	.23	10/22/73	2.73	07/18/76	03/08/11	65
RICKETSON, LORENE	07/12/73	.36	11/21/73	.02	11/30/73	03/10/09	64
REYNOLDS, SARAH	08/25/72	1.43	02/01/74	.17	04/06/74	02/06/30	44
CRANE, MAYME	07/12/73	.72	04/02/74	.51	10/06/74	02/24/27	47
SUMMITT, ROBERT THOMAS	11/27/73	.61	07/11/74	.08	08/12/74	10/02/47	26
ROUNDTREE, EDWARD MARTIN	08/04/71	3.01	08/09/74	1.62	03/23/76	08/31/51	24
BRYANT, CHARLES KEVIN	04/12/73	2.52	10/20/75	1.37	03/06/77	07/27/62	14
TORSTRICK, AUGUSTA	08/25/72	3.63	04/13/76	.25	07/15/76	03/12/18	58
WILHOITE, SANDRA GAYLE	08/12/71	4.81	06/04/76	.07	07/02/76	04/29/50	26
CROMWELL, JONAS WESLEY, JR.	04/16/73	3.38	09/02/76	1.07	09/30/77	02/15/61	16
ROGERS, JOSEPH JULIAN	04/03/73	3.56	10/27/76	1.11	12/09/77	07/22/39	38
TURNER, DONNIE LEE	06/11/73	3.42	11/12/76	.46	04/29/77	07/05/59	17
REYNOLDS, KAREN	05/10/73	4.06	05/31/77	.13	07/21/77	04/05/53	24
MORGAN, TIMOTHY	07/24/75	2.04	08/10/77	.37	12/25/77	04/21/68	09
	AVERAGE......... inpatient years of life at Hazelwood	2.31	AVERAGE... years of life after transfer from Hazelwood	0.73		AVERAGE.. age at death	34.46

DEATHS AT HAZELWOOD

NAME	ADM. DATE	IN-PATIENT YEARS	DEATH DATE	AGE AT DEATH	BIRTHDAT
Averbeck, Todd Alexander	6-01-71	.50	12-02-71	11	2-25-60
Jessee, Linda Gayle	7-07-71	2.02	7-15-73	16	8-10-56
Johnson, Ray	7-08-71	1.71	3-26-73	25	8-30-47
Browning, Katherine	7-13-71	.38	12-01-71	15	5-13-56
Reed, Carrie Etta	7-13-71	2.60	2-18-74	21	4-04-52
Webster, Stanley Michael	7-29-71	2.44	1-06-74	17	8-06-56
Welsh, Donald Edward	7-29-71	4.33	11-28-75	22	2-27-52
Boone, Deborah Karen	8-05-71	5.61	3-14-77	21	8-15-55
Sexton, Carl Lynn	8-11-71	2.81	6-04-74	17	7-08-56
Livingston, Vickie Lynn	8-18-71	1.08	9-18-72	15	11-02-56
Gocke, Cynthia Ann	8-18-71	5.02	8-25-76	18	12-05-57
Blandford, Wanda Lou	8-18-71	1.21	11-04-72	15	12-14-56
Holeman, Andrew Bennett	12-08-71	1.35	4-17-73	15	1-12-58
Woods, Mark Nickolas	12-20-71	2.00	12-22-73	8	3-14-65
Crenshaw, Gary Wayne	12-20-71	3.01	12-26-74	14	5-23-59
Polley, Alma	8-18-72	1.44	1-29-74	58	8-20-15
Brake, Felecia Frederick	8-18-72	2.40	1-14-75	30	6-12-44
Richardson, Floyd E.	8-25-72	.86	7-05-73	50	2-14-23
Spainhoward, Tabatha Carol	4-02-73	3.65	11-26-76	9	6-14-67
Bradford, Dara Kay	4-17-73	.49	10-16-73	6	2-02-67
Morrissey, William McMurray, Jr.	5-10-73	3.13	6-26-76	14	7-14-61
Rayhill, Dawn Bliss	5-10-73	.05	5-29-73	23	12-13-49
Thompson, Sharon Gayle	5-10-73	4.75	2-11-78	19	9-22-58
Moberley, Lawrence Barry	6-13-73	1.91	5-13-75	16	4-10-59
Rodgers, Florene	6-18-73	2.34	10-21-75	32	3-15-43
Brown, Frances Susan	6-19-73	.03	7-03-73	11	12-19-61
Douglas, Gaylon Gene	6-20-73	.03	7-03-73	15	7-07-58
Greer, Douglas Welliford	7-05-73	1.58	2-05-75	32	4-28-42
Page, James Bland	7-05-73	.86	5-16-74	51	3-03-23
Wright, Earl Turner III	7-10-73	.27	10-19-73	16	9-02-57
Speed, Gary Stanley	7-12-73	3.66	3-11-77	25	8-07-51
Johnson Roy Gene	9-07-73	0	9-10-73	27	9-02-46
Kahle, Douglas Scott	2-11-74	.24	5-10-74	6	7-01-67
Lewis, Sharon Marie	5-09-74	3.46	10-23-77	24	12-16-52
Rider, Alice Michelle	9-13-74	1.46	2-28-76	15	8-06-60
Kirkpatrick, Charles Russell	12-17-74	1.04	1-01-76	5	2-25-70
Dethridge, Melissa Ann	4-15-76	.58	11-13-76	14	6-26-62
Manning, Charles King	5-08-73	4.79	2-21-78	13	12-30-64

AVERAGE YEARS AT
HAZELWOOD AT TIME
OF DEATH............ 1.89

AVERAGE AGE
AT DEATH... 20.02

It should be noted that nearly all of the children who died at Hazelwood were very delicate children and were admitted in very poor condition. Examples: (at random)

Averbeck- very frail, prone to upper respiratory infections, chronically ill, totally helpless. Had to be turned, etc.

Douglas- Admitted as an emergency. Dehydrated, not eating, had bleeding ulcer. Very frail. Totally helpless.

Rayhill- Congenital heart disease, frequent cyanotic spells wherein could not breath. Frequent upper respiratory infections, Very frail and totally helpless, etc.

WHEREIN--those residents who were placed out of Hazelwood were in very good health with no serious or problem medical conditions. All they required was good basic day-to-day maintenance care.

ATTACHMENT TO THE PLACEMENT STUDY

2922 Woodcroft Cir.
Carrollton, Texas 75006

March 1, 1984

Roderick A. Dearment, Chief Counsel
Senate Committee on Finance SD219
Dirksen Office Bldg.
Washington, D.C. 20510

Dear Mr. Dearment:

I wish to be on record as strongly supporting SB 2053, the "Community and Family Living Amendments of 1983". This bill is absolutely essential if we are to provide "state of the art" services for thousands of persons in our country with mental retardation. It is time we directed medicaid dollars into appropriate channels to allow the development of human, cost effective, non-warehousing productive services for our citizens in their own community.

Present Medicaid funding is directed to the costly maintainance and perpetuation of primarily inappropriate services in large institutions. This gives no choice to the hundreds of thousands of persons with retardation who will need services for the near and long term future. It does not allow these people to utilize and complement their educational and vocational training provided by enlightened teachers and trainers in the past generation.

Substantial Medicaid funds must be diverted to community sources. These services are are badly in need of stable funding. These services are cost effective, desirable and better for both retarded persons and our society at large. Let me tell you how I know this to be true.

My son had to reside in a large state institution for more than twenty years. He is non verbal and was judged to be severely retarded. His state school evaluation team considered his living skills and socially adaptive behavior insufficient to warrant a classification to enable him to live in a group home. His I.Q. was variously reported to be from 18 to 40. His living conditions in the large facility included poor or non-existant developmental programming, inadequate and insufficient medical care, isolation from society, boredom, sexual abuse and other serious physical abuses. Because of the stultification of the environment and inadequate and untrained staff (usually busy with crisis intervention) Micky was unable to demonstrate the living skills which I nurtured in his home visits (about 1/3 of the year).

Small wonder that an institutionalized staff in an institutionalized environment could see little potential in their clients. Small wonder that the staff expected (and therefore received) limited response from clients. Small wonder that the society outside perceived these state school residents to be incompetent, unproductive, dangerous and different. Small wonder that a resident was judged to be incapable of handling a table knife when he was never provided with the opportunity to use one. Small wonder that a client displayed little initiative in an environment where one is required for staff convenience to stand in line for everything--meals, tooth brushing, shaving and in a line of naked persons for showering.

Because I believed in Micky's skills, potential and the state-of-the-art and through my own efforts over a period of years Micky moved into a small group home in the community about 18 months ago. A recent evaluation places his I.Q. at 47. The evaluation notes a rise in his socially adaptive behavior from a six to a nine year level. He keeps his own room, washes his own clothes, helps prepare meals, makes his own lunch, uses bus transportation, works in a workshop and comes in contact with many many folks in the community. Most importantly he has become proud of himself and is a productive member of society.

Community groups are now beginning to accept and understand as well as to help persons with retardation. A feature of Micky's group home program is bowling on Saturday mornings. At Christmas time the manager of the local bowling alley presented each resident with a new bowling ball of their own. Generic services such as pools, restaurants, parks,movies, museums and churches now belong to persons with retardation too.

I'm aware that many persons with institutionalized relatives oppose this redirection of funds. They too had no choice of service delivery systems when they needed choices. After many years they dare not or will not question the viability of that system. Their "problem" is being taken care of, they rigidly believe. They have time to write letters, testify and to attend meetings organized by providers with vested interests who urge them to "save their schools".

I suggest to you that less than 10 years ago in Texas the state was supporting it's own massive institutional system without Medicaid funds. The system can survive without Medicaid funds entirely as it once did. Institutional supporters praised their system then as they do now. We must not allow a small percentage (but very vocal) of selfish persons deprive thousands of persons with retardation of the choices for a decent life.

I can think of no better endorsement of SB 2053 than Micky's story. Medicaid dollars have been locked for too long into large institutional funding while small facilities go begging. We must have Federal funding flexibility so that thousands of Mickys might be removed from a suffocating and limited lifestyle to one which more nearly approximates yours and mine.

Sincerely.

Ellen J. Huffman

Ellen J. Huffman

HARC

HOWE ASSOCIATION FOR RETARDED CITIZENS

a not for profit organization of people working for people

I am testifying in the name of Howe Association for Retarded Citizens, the ARC group which advocates for Howe Developmental Center, a State Institution housing 771 developmentally disabled residents with a variety of handicaps. We're told that the largest portion of money goes to institutions which care for only 13% of the DD population. We do not dispute this fact, however we want to call to your attention that the 13% in institutions includes the more severely handicapped, medically, physically and behaviorally involved who have the greatest need.

I recall that one of the speakers at the last National Convention, obviously a parent of a higher level less handicapped retardate, indicated that for years she had wondered why she was even a member of this organization because the emphasis had always been on support of the institutions. As I listened to her I couldn't help but reminisce about my early days as a member of an ARC Unit, when we urged the parents of children in Educable Classes to join with us in working for the retarded. They wanted no part of us then, their children were not in the same category with ours. At that time the only option we had for placement was the Institutions and that was only after years on the waiting list. The few private schools which existed were extremely restrictive and very expensive. None of us were happy to place our charges in State Institutions, particularly with the conditions as they were then, however there was no alternative. There were no Education, Recreation or Vocational Training Programs in the community for severely and profoundly handicapped. As those programs came into existence and some housing began to surface in the community, a few of our residents were transferred to those facilities, however it was noted that residents in State Institutions

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First Vice President-George Muligano, 6 Clubhouse Drive, Willowbrook, Illinois 60514
Second Vice President-Fred Boland, 48 East 160th Place, South Holland, Illinois 60473
Secretary-Walter Humble, 6350 North Lakewood, Chicago, Illinois 60660
Treasurer-Emily Knoske, 1232 Blanchan Ave., LaGrange Park, Illinois 60525

were very carefully screened. It is not our intention to criticize, but merely to point out that the more severe, hard to manage retardates, sometimes needing much medical care, are those remaining in the institutions.

As far back as 1980 we had the Compliance Plan which called for deinstitutionalization here in Illinois. I quote John Harcourt from an article in the ARC/I Newsletter, "The Compliance Plan was written for the purpose of obtaining a waiver from the Federal Government to allow the State of Illinois to begin receiving Title XIX funds for beds which currently do not meet anyone's standards and, therefore, focuses on institutional changes. By attracting Title XIX funds now, money will be available for use in Community Develment and for upgrading institutional services". This plan called for the reduction of population at four institutions--Dixon, Lincoln, Shapiro and Murray. I'm not too familiar with the progress made in complying with that plan in the other three institutions, but I do know that the plan was eventually approved by the Government and extra Federal Dollars were poured into Illinois under this waiver agreement for Dixon, even though the units did not meet ICF/DD standards. Renovation of buildings was begun and some residents were transferred closer to their homes. The target population figure at Dixon was somewhere around the 600 figure by 1982. After much of the renovation had been completed during which the residents suffered as a result of the many moves which had to be made from building to building due to the repairs being made, the Governor then made the decision to close Dixon and the residents were, for the most part, transferred to other State Institutions. Population at Shapiro increased to 800 plus and Howe zoomed from 480 to 772 by the time Dixon was closed. Ludeman and Waukegan were required to increase the population in each of their houses from 8 to 10. Of the 695 residents transferred as a result of the closure of Dixon, only 34 received community placement.

An additional plan was set in motion last July for reducing the population at State Institutions. Medicaid Waiver Funds would be granted to Community Organizations willing to accept retardates from Institutions in Illinois. The Department, with Federal approval, plans to transfer these funds if 75% of the residents accepted for the new facility will come from State Institutions. Budgets at the beginning of this fiscal year for the Institutions were based on the anticipated gradual reduction of population due to this plan. 249 residents are to be moved to the community from the State Institutions in Region II alone. To date, I'm not aware of any movement out of the institutions to group homes in this region and all of our institutions are operating at a deficit due to this.

Four years after being told that the Compliance Plan was the answer to deinstitutionalization we still have had very little movement from the institution to the community. Now we're being told that the threat of removing Federal Funds within 10 years will result in the establishment of group homes 15 or under,for 5000 retardates now in State Institutions plus those in private institutions and all in the community waiting placement.

We're told that residents will not be dumped but will only be transferred when appropriate community services are available. Will those services include all that now are available to our residents in the institutions? Will there be a doctor and nurse on call around the clock in those group homes? Will Vocational, Educational, Psychological and Recreational Services be available to each and every one of those group homes at the much reduced costs that have been publicized? Yes, we're assured that the transferred funds will be available not only to provide living arrangements but all supportive services necessary, but we can't understand how it is possible to guarantee that the services are available before the resident is transferred, if, as we're told, the money is to follow the resident. What about seed money for the establishment of those group homes and the services needed? Are we going to be dependent upon the State for these funds? Illinois' reputation in this area is nothing to brag about. We understand that since 1977 only 16 group homes have been opened in this state. Lack of seed money is one of the important complaints to say nothing of the zoning problems.

Regarding the cost issue, ARC claims that a study made by the Hubert Humphrey Institute for Public Policy proved that only by doing what SB 2053 proposes,could there be substantial savings to both Federal and State Governments. Upon investigating we have learned that the study referred to was made in 1980 and it's no secret to any of us that only the more tractable retardates with the most skills were welcome in the community then, or in some cases even now for that matter. Bill Copeland of the Hubert Humphrey Institute informed us that a later study was made of the severely and profoundly mobile retardate with no behavior problems and it was determined that community care costs for that group were 80% of the institutional care. If they ever get around to making a study of a similar group but also include some who are medically fragile and behaviorally involved, maybe we'll get a more realistic comparison of costs. After all, our State Institutions are expected to care for residents who have any or all of these handicaps and the costs are averaged out over all of their residents.

We're assured that the bill does not call for the closure of state operated institutions and that they will be required to meet ICF/DD standards even after Medicaid Funds have been cut off. Without the threat of losing those funds, how can we guarantee that the standards will be met? We suggest that at the end of the time period for loss of Federal Funds, those residents left in State Institutions will merely receive custodial care at the lowest level and we will have lost 20 years of progress in the care of the retarded. Yes, some improvements will have been made in the community but in this State I fear the most severely handicapped, physically and behaviorally involved, will remain under the State's wing.

We are not opposed to group homes in the community. We strongly support funding for that purpose and readily admit that some residents who are now in State Institutions can profit by transfer to the community, however we do not feel that group homes are the answer for all retardates. We need a continuum of services and we feel this is what our National and State Organizations should be promoting without sacrificing funding for one end of the continuum in order to promote care at the other end. In our opinion this bill is not the answer to our problems and should be scrapped. We'd like to see a new bill which would avoid discrimination against any portion of our handicapped individuals and provide the services needed for all of our loved ones.

Bernadette Sullivan, President
Howe Association for Retarded Citizens
798 Linden Avenue
Elmhurst, Illinois 60126

STATEMENT OF MR. & MRS WILLIAM R. JOHNSON, PARENTS OF CAROLYN MARIE AND PAMELA CATHERINE JOHNSON, CHICAGO, ILLINOIS

For me having to write this statement on behalf of my daughters makes me very angry at the political structure of the United States. This country as I believe stands for freedom, but what you are trying to do with this Senate Bill 2053 is to take away the freedom we now enjoy. I feel that as parents of two mentally handicapped children, we should have the freedom to choose the type of school or residence that is best suited for them. I know you you do not know them, so how can you tell me or them that a residential school of 10 or less beds is best for them and one that has more is no'good for them. For you to make this judgement is as absurd, as it would be for me to tell you what is best for your children whether handicapped or not.

I am also disappointed in you as human beings with insensitive statements about how costly things are with the mentally handicapped. How much money is wasted in aid to other countries, military hardware, political junkets, and needless government printing. The only programs senators and congressmen support are the ones that serve their political ambitions. I would like to say who needs you, but I cringe at the day when I leave this life and my daughters are left to your cost cutting whims.

In closing we do not support Senate Bill 2053 and will not support any admendments to it. Withdraw this bill from consideration.

Mrs. Willis King
Formerly Board Member and Officer,
The National Association for
Retarded Citizens

March 12, 1984

Roderick A. De Arment, Chief Counsel
Senate Committee on Finance
Dirksen Building
Washington, D.C. 20510

Members of Senate Finance Committee
Subcommittee on Health:

I came to the hearing recently on Mr. Chaffee's S-2053 and listened attentively to the testimony. I have concluded that, although the bill could conceivably serve my own family interest, its final thrust is destructive. Its implementation will destroy many very good things a great number of dedicated people have worked lifetimes to achieve. My own first Congressional hearing on behalf of the mentally retarded was some time in the fifties. Moreover, it will accomplish only a fraction of what it intends.

To address the two arguments most frequently used in its favor, the increase in beneficial care and personal attention clients will receive, and the decrease in cost:

Sister M. Antonette Boroncini (Administrator for St. Mary's Training School, Alexandria, Louisiana. See testimony on Senate Finance Committee, Subcommittee on Health hearing on S-2053 on February 27, 1984) described the benefits of the loving care and attention to individual persons in small groups in the idyllic setting of her Catholic project. But it is most certainly not the small size that produces these results. It is the devoted, practiced staff, supervised by an attentive, frequently present, Mother Superior type, who teaches and trains and checks often.

This bill will not produce this kind of care or this kind of situation. In fact, it will frequently do quite the opposite. The bureaucratic choice of "care providers" is by a kind of bidding process on the part of the government unit, a process a little like a slave auction, except that the human beings in question go to the lowest bidder instead of the highest. The winning entrepreneur will hire his staff as inexpensively as possible. There may be some training since this kind of personnel is frequently either very young or very old and unskilled. There will no doubt be a caseworker who, given the usual case load for government social workers, may drop in now and then. But what happens in these small, isolated units will most surely be almost entirely in the hands of the casual caretakers currently in charge. The nature of the clientele's disability will naturally discount any observations they might make--if they were so inclined or able to do so.

There is a flyer somewhere in the current propoganda which is an assembly of selected inflammatory headlines about malfeasance in institutional care. I would suggest that any casual reading of The Washington Post over the period of a month or two would provide an equally grim series of headlines about disaster in nursing homes, group homes, and similar community placements where patients from St. Elizabeth's have been placed recently in the metropolitan area. These events will occasionally take place in either situation. But they are less likely to be known and therefore corrected in isolated units. In a well-run accredited, small, modern institution with an excellent professional staff (like Great Oaks, Prince Georges County, Maryland) they will happen less often and are more likely to be recognized and corrected.

The statistical arguments about costs are worth examining as well. Dr. David Braddocks' statistics (See Senate testimony on S-2053, Expenditure Analysis Project, Dr. David Braddock, Director, Institute for the Study of Developmental Disabilities, M.R.D.D.) were thorough and accurate. But precise parallels are very difficult to establish because it is almost impossible to assemble comparative cost figures for two such disparate financial and operative situations. Some common sense conclusions remain no matter what gymnastic configurations the figures may assume.

One selected example is suggestive. The fact that costs in an institutional setting go up as the institution decreases in size is not, except peripherally, a function of the change in size. It is the change in the nature of the population, which becomes concentrated on a high-cost clientele which require much specialized care and equipment. If they have this kind of care--and a civilized humanity since Dorothy Dix believes that they should have--it will cost as much, or more, divided into small repetitive units. And again, the caretaker will be no more able, and possibly less able under inconvenient circumstances, to give the professional as well as the loving care which is desirable. This high cost for the care of the severely handicapped is the figure which causes the average cost for the care of the mentally retarded in institutions to seem so high. The higher functioning mentally retarded are less expensive to care for wherever they are.

There is another possible result of ever expanding community care which needs to be faced squarely. There are now in the community a number of high functioning mentally retarded individuals who could conceivably become eligible. Any anticipated decline in cost would rapidly vanish in any such exploding use. When all Medicaid funds are sharply curtailed, which seems not unlikely, there will surely ensue a confused state of affairs with no resource for the truly infirm and handicapped if the good institutions have lapsed by that time.

It reminds me of the generation of college students who left the dormitories for apartments in droves ten years ago and who are now back in the dormitories--when there is room for them.

I am not sure how persuasive personal experience is, but I can give you an example of what "less restrictive environment" means when there is real pressure to deinstitutionalize a population.

Our son is currently living at Great Oaks Center in Maryland, an example of an excellent small institution. He is a low level Down syndrome young man, thirty-seven years old, with a mental age of about five. He has no intelligible speech, is blind in one eye, and rapidly becoming blind in the other. At Great Oaks he has had the benefit of a well-chosen, community day placement, and good professional direction in other areas. Over the eight years he has spent there, he has improved dramatically. Now he is a pleasant, cooperative individual who likes to make beds, set tables and clear them, and generally be orderly and responsive. On that campus he can go where he pleases, since he is familiar with the terrain, and since if he speaks unintelligibly in that place he will be listened to patiently. If he wanders into the roadway, no one will smash him. Then he can return to Cottage 3 to a big common room with twenty-four to thirty colleagues to share the company and music and so forth. In that environment he can go on and be blind, secure, at home, and still, as far as possible, free.

Great Oaks, however, must make room for two hundred clients from another institution which is being closed. So Christopher, as a result of profiting from their training, is to be transferred to a "less restrictive environment," a house in a suburb. There he will not be able to step out of the house onto the busy street unattended. Except for the times spent at his sheltered workshop, unless he is taken somewhere on a special expedition, he will be shut up in that small suburban living room with a few colleagues for the foreseeable future.

Some mentally retarded can be happily situated in community placement and perhaps thereby save the State some money. This is most likely to occur in areas with a high tax base and an aware, articulate citizenry, (cf. Montgomery County, Maryland). But there are now many fine small institutions who also do an excellent job for their clientele. They both excell in their own spheres. Let us keep them both.

The terrible Mr. and Mrs. Squeers in Mr. Dickens' Nicholas Nickleby would not suddenly change their pattern of behavior if Dotheboys Hall were reduced to five or ten inmates. Poor hapless Smike would be just as hapless in what Mr. Squeers doubtless would call "a less restrictive environment."

Frances Hall King

Mrs. Willis King
Formerly Board Member and Officer,
The National Association for
Retarded Citizens
Associations for Retarded Citizens,
Georgia, Maryland, District of Columbia
Active in related areas until early seventies

Frances Hall King
5336 Wapakoneta Road
Bethesda, MD 20816

Spreading the Light
Scattering the Darkness

The Lutheran Church-Missouri Synod

1333 South Kirkwood Road, Saint Louis, Missouri 63122
Telephone: 314-965-9000

Board for Social Ministry Services

February 23, 1984

Senator Dave Durenberger
Ms. Lynn Blewett
Senate Office Building
Washington, D. C. 20510

Dear Senator and Lynn,

Let me thank you for the assistance you have given me in pointing out the direction that I might take as I expressed concern over S. 2053.

Since I will not be at the hearings, let me request that the enclosed material be submitted for the record. This is my report to the Board of Directors of The Lutheran Church-Missouri Synod concerning this issue.

Let me request, further, that you advise me at any future stage of developments when legislation is pending. My denomination has no small interest - and a substantial stake -- in issues such as this.

Sincerely yours,

Eugene W. Linse, Executive Secretary
Board for Social Ministry Services
The Lutheran Church-Missouri Synod

Enclosures

EWL:gc

Agencies of The Lutheran Church-Missouri Synod providing Residential Care for the Developmentally Disabled

At my request, our Secretary for Agencies and Institutions, Mr. Virgil Fuchs, has provided a brief summary of the agencies, services rendered, cost of facilities, annual budget and voluntary contributions to these agencies. These agencies would be materially affected were S. 2053 to be enacted in its present form. It would be contrary to current public policy emphasis to terminate program activities in which such a large measure of volunteer work and charitable contributions have contributed directly and subsidized the activities involved in providing quality care to the residents of these facilities.

CEDAR LAKE LODGE, LAGRANGE, KENTUCKY

Cedar Lake Lodge was established in February of 1970. In a residential treatment center licensed as ICF/MR, 76 residents are served. Counseling is also provided for their families. Plans are underway to open group homes in 1986.

The current value of property is approximately 3.1 million dollars. Cedar Lake Lodge has an endowment fund currently of $700,000. With 110 employees, the current annual operating budget is 1.9 million dollars.

Of the operating budget, 10% is charitable subsidy.

GOOD SAMARITAN LUTHERAN HOME, CYPRESS, TEXAS

Good Samaritan Lutheran Home was founded in 1968. It serves 40 residents in a 24 hour residential care facility and special education program. It is not currently licensed as ICF/MR. Ten residents are served in a group home, and two additional group homes will open in the near future, one serving 16 residents and the other serving 6 residents.

The current value of property is approximately 3 million dollars and endowment trusts is currently valued at $862,000.

With 48 employees, the annual operating budget is $1,180,850. Of the total operating budget, 62% is charitable subsidy.

GOOD SHEPHERD LUTHERAN HOMES, TERRA BELLA, CALIFORNIA

Good Shepherd Homes were founded in 1955. One hundred-forty residents are served in ICF/MR facilities. Forty-two residents are served in 6 group homes, 32 residents are served in a HUD 202 group home and apartment project. Twenty-seven people are served in 14 apartments. Four hundred residents are served in community care facilities under California license, and plans are in the process to disburse these residents to ICF/MR facilities and to group homes.

The current value of property is approximately 12 million. The agency is assisted by a foundation with a value of 5 million dollars.

With 500 employees, the annual operating budget is 10 million dollars. Of the annual operating budget, 25% is charitable subsidy.

BETHESDA LUTHERAN HOME, WATERTOWN, WISCONSIN

Bethesda was founded in 1904. Five hundred residents are served at the Watertown, Wisconsin campus, including residential, skilled nursing, and ICF/MR services. In addition, 72 residents are served in 10 group homes around the country. The agency is also licensed for children's services in mental retardation.

The value of properties is approximately 27 million dollars. A foundation serving Bethesda is valued at 3 million dollars currently.

With 600 employees, the annual operating budget is 14 million dollars. Of the annual operating budget 50% is charitable subsidy.

VLF/cc
February 6, 1984

REPORT TO THE BOARD OF DIRECTORS

S. 2053: ANALYSIS AND COMMENT:

The Community and Family Living Amendments of 1983, S.2053, was introduced in the United States Senate by Senator John Chafee (R) R.I., on November 4, 1983. The measure has been referred to the Senate Finance Committee where hearings have been scheduled by the Subcommittee on Health on Monday, February 27, 1984. Announcement of the hearings evoked a very large number of requests to testify before that subcommittee, largely from opponents of the proposed legislation. Hearings to be held on February 27 are the third in a series of hearings on long term health care. Chairman of the Subcommittee on Health is Senator Dave Durenberger (R), Minnesota. In announcing the hearings, Senator Durenberger said in part... "the Subcommittee is interested in the development of an integrated long-term care delivery system which provides an appropriate level of care, in an appropriate setting, on a cost-effective basis." Senator Durenberger said that the Subcommittee is interested in hearing from the Administration, the states, providers and consumers... particularly in comments on the possible benefits to be derived for the disabled from the Medicaid program as the result of the proposed shift to community-based care; the feasibility and obstacles to providing such care, and the experience available from existing community based facilities for the disabled.

Background:

In 1975 rules were issued allowing residents of Intermediate Care Facilities for the Mentally Retarded (ICF/MR) to be eligible for Medicaid. The goal of the ICF/MR program is to help each developmentally disabled person reach his/her maximum potential. Each resident is to have an individual active treatment and training program. The assumption is that the resident can develop beyond current capabilities.

ICF/MR facilities are licensed and monitored by the states and must meet Life Safety Code provisions and many other state and federal standards. (There are 560 specific federal standards alone governing such facilities.) Facilities are inspected for quality of programming and treatment of residents, for physical safety and sanitation and for utilization, reviewing the level of care appropriate to meet residents' needs.

Professional services are extensive. They include nursing, dental, medical, psychological, physical and occupational therapy, speech pathology, audiology, therapeutic recreation, pharmacy, social and dietary services. Organizations such as Good Samaritan, Good Shepherd, Cedar Lake Lodge, and Bethesda provide an additional dimension of service of no small significance - the religious atmosphere of the home and the opportunity for worship and religious experience for its residents. ICF/MR programs serve persons with a broad range of needs: blindness, cerebral palsy, epilepsy, and mental retardation. Some ICF/MR residents have no next of kin and are wards of the state for a number of reasons, including abuse and rejection by parents.

In 1978 Public Law 95-602 was enacted to define more clearly the nature of disability in order to qualify for Medicaid assistance. From 6 to 15% of the mentally retarded live in some form of residential setting; the majority are cared for at home. Residential settings vary in size from the very large state-run institutions to cottage-type residential facilities for 8 or 10 individuals. Local public sentiment, often hostile to the establishment of a facility in a given neighborhood, creates an added burden in attempting to care for ICF/MR residents close to their former residence.

Prior to the time that S.2053 was introduced in the Senate, a number of meetings produced modifications in the then-proposed legislation. However, the thrust of the legislation remains the same - to deinstitutionalize the mentally retarded. Major proponent of the legislation is the Association of Retired Citizens. Opponents include the American Health Care Association, which represents some 8,000 institutions providing one form of care or another, as well as Parents Network, the Child Welfare League and National Homes for Children.

Substance and critique of the proposed legislation:

There are some admirable characteristics in the proposed legislation that should not be dismissed lightly. Its purpose: to promote full participation of the severely handicapped in community life. Sections of the bill state that severely handicapped persons are able to learn and to contribute to society and should be encouraged to lead productive lives. Emphasis on the development of settings that emphasize freedom and maximum participation are commendable. One section of the bill stresses the importance of small facilities and argues that they should be established in residential neighborhoods. These are all worthwhile objectives.

Defects in the proposed legislation are readily apparent. To the extent that S.2053 stresses the small institution over against any other size and would withdraw from federal funding any institution in excess of 10 persons, the proposed legislation misses some important considerations. Small is not necessarily good. Big is not necessarily bad. The bill should address the question of quality of care rather than one of size. In many cases the range of services the disabled need are not available in small facilities. Stated another way - the bill proposes a simplistic answer to a complex social problem. The question of the size of an institution is relevant only in the context of available services that are to be measured in terms of quality and diversity. Effectiveness of treatment is quite forgotten in the concern over numbers. No consideration in the legislation as proposed is given to the quality of services provided by a trained staff, very necessary if residents are to learn those skills that will equip them to function effectively and live as independently as possible.

The bill also suffers from a lack of discussion of standards, provides no safeguards against patient abuse, fails to discuss sanctions to provide for enforcement, and may well be considerably more expensive than what Medicaid is willing to pay. The impact of the legislation as proposed is that it would withdraw funding from good facilities, such as Bethesda, Cedar Lake Lodge, Good Samaritan and Good Shepherd Homes, that provide services that enable the mentally disabled to learn skills needed for independent living. At the same time the bill would transfer funding to facilities with an unknown ability to care for the mentally disabled.

However well-intentioned the legislation is - to deinstitutionalize care for the disabled - major shifts in the delivery of services that lack adequate preparation, facilities available to accept responsibility for such a transfer, or at least the probability that the benefits envisioned would outweigh the risks and pitfalls such a change might well engender, are ill-conceived and in need of reconsideration.

Summary and Conclusion:

From a national perspective, what seems to be needed is a healthy mix of institutions, large and small, that minister to the diverse needs of the handicapped in our society. Emphasis needs to be placed on QUALITY OF SERVICE rather than on size as a determinant for funding, whether from Medicaid or from any other source. Institutions that are public as well as those that are private, large and small, regional and local are all part of a balanced approach to the care of the severely disabled.

As constituted, S.2053 ignores the history of service and the quality of care that has been recognized nationally, that has earned the continuing endorsement and support of large constituencies, as in the case of Bethesda Lutheran Home - one of many religiously related quality-service institutions in America today. If the effect of legislation as proposed in S.2053 is to disavow the services of such institutions, our society will be poorer for such a legislative decision.

A Political Note:

S.2053 has been scheduled for hearings on February 27. Social Ministry Services will monitor that hearing and report on it. No companion bill is scheduled in the House of Representatives, nor are there any known sponsors for such legislation at the present time. The political implication of S.2053 in an election year are such that few congressmen would have an interest in endorsing legislation that has the potential for the arousal of public sentiment that could be detrimental in an election campaign.

While interest has been generated in Lutheran circles, efforts to engage in significant political action at this time do not seem warranted. S.2053 in its present form has aroused more opponents than it has garnered supporters. In any case, organizations such as the American Health Care Association, with whom we are in touch, have promised to keep us apprised of developments, will coordinate response to this, as well as to other proposed legislation, and has requested our cooperation at the information as well as the action level of response. Through testimony before the Senate Subcommittee our concerns will be given ample consideration.

Eugene W. Linse
Board for Social Ministry Services
January 31, 1984

EWL:gc
Rev. 2/20/84

Statement by

ARTUR MAGER

Submitted for inclusion in the printed record

OF THE SENATE FINANCE SUBCOMMITTEE ON HEALTH

HEARING ON COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983. S. 2053

To be held February 27, 1984 in Washington D.C.

Mr. Chairman and Members of the Subcommittee:

As a parent of a blind, severely retarded daughter, 2-nd Vice President of the Association for Retarded Citizens of California, past Chairman of Los Angeles Developmental Disabilities Area Board, past President of the Exceptional Childrens Foundation and a recipient of ARC-CA's Golden Rule Award, I would like to call the Subcommittee's attention to the many objectionable provisions of S. 2053 and urge you to defeat this potentially very harmful bill.

As you know, S. 2053 provides for amendments to the Medicaid laws which would substantively widen Medicaid eligibility and coverage, but deny assistance to severely disabled individuals residing in facilities which have more than approximately 9 beds. All larger residential facilities would be phased out over a 10 (in some very special cases, 15) year period. Since such facilities are currently serving primarily severely and profoundly, often multiply handicapped, mentally retarded individuals, these would be the people most adversely affected by this ill conceived legislation.

But let me list and explain my concerns:

1.Contrary to often repeated assertions, serious research into the matter of desirable size of residential facilities for mentally retarded people (Ref. 1) discloses lack of any substantive evidence that large facilities are "bad", just because they are large, and similarily there is no evidence that small facilities are "good", just because they are small. Therefore the proposed phase-out of large facilities is grossly inappropriate and irresponsible because some of the existing large facilities (such as the newly remodeled, to provide homelike settings, Lanterman State Hospital and Developmental Center in Pomona, CA) are delivering much needed, excellent quality, developmental care. Moreover, it should be noted that this simplistic use of size as a sole determinant of the quality of care is particularily wasteful today because many States have recently spend hundreds of millions of dollars to improve their large facilities.

2.According to serious researchers the selection of "optimal" residential facilities for mentally retarded people depends on local environment and local constraints. The matter of size should be related to a person's age, past experiences, ability level, current life situation and his or her physical, psychological or medical requirements. Because of that, a properly balanced, but full, spectrum of various kinds of facilities is required. Legislative imposition of a single mode residential system is highly inappropriate since it would deny some people the right to care in facilities that they need.

3. The proposed Medicaid restructuring does not address the lack of incentives for the establishment of community based facilities. Certainly not Medicaid-certified facilities, capable of delivering care appropriate for the needs of profoundly and severely mentally retarded people. It will dismantle large facilities without any assurance that the needed community based residences will come into being. In California alone I estimate that more than about 1700 new facilities would be required to house the population currently residing in large facilities. Nationwide probably some 170000 to 200000 new facilities would have to be opened. Because of that, the restructuring is potentially harmful, physically and developmentally, for the severely and profoundly mentally retarded individuals. It will repeat the tragic mistake we made when deinstitutionalizing the mentally ill at an uncountable cost in human suffering, a mistake which today, in California, we are trying and finding so expensive to correct.

4. It is very difficult, if not impossible, to accurately determine whether the costs of care in large facilities are any different than the costs, at the same standard of care, in small facilities. Most comparisons of cost neglect the much greater need for the personal care of the

severely and profoundly mentally retarded population, as well as, start-up, monitoring and phase-out costs which the proposed restructuring would impose. Indeed, the California Legislative Analyst's data (Ref. 2) indicates that the costs of similar services in community based facilities, including start-up, are slightly higher than in comparably remodeled state hospitals (including remodeling costs). This means that the proposed restructuring will not only fail to reduce costs, but, even for the same expenditures, it is likely to lead to a reduced standard of care for the severely and profoundly mentally retarded people currently residing in large facilities. And when the major cost increases connected with the proposed expansion of Medicaid eligibility and coverage are considered, then it becomes obvious that the aim of this legislation is not to reduce costs, but to transfer the Medicaid support from those that need it most to those who can, to a large degree, be self-sufficient. Isn't this contrary to the very purpose of Medicaid?

5. The transition time provided in the bill is pitifully inadequate. Nebraska, which since 1968 has been reducing it's institutional population of only 2400 persons, 17 years later, by 1985, will still have some 250 in institutions. This slow process was deliberately introduced in 1972 to stop inhumane "dumping" (that is, discharge from large facilities regardless of the existence of appropriate community based facilities). And in spite of this telling experience this bill proposes to phase-out large facilities within 10 years! Apparently the cost of human suffering is unimportant since most of the severely and profoundly mentally retarded people cannot speak, much less speak for themselves.

6.Periodically, in our daily newspapers, we see stories pertaining to the abominable state of community based residences. Many problems of these residences may be traced to the fact that privately owned facilities are extremely unstable, closing overnight without any consideration of what that will do to their residents. As a result of these forced transfers the residents live in perpetual threat of a crisis. Moreover, monitoring and licensing of community based facilities is very superficial and the constantly changing staff in these facilities lacks any training whatsoever. I am sure that you can readily see what that would do to even "normal" people. For sensorily deprived, severely and profoundly mentally retarded individuals this is an incessant psychologically and physically injurious trauma often resulting in death (Ref. 3). Hardly a normal, homelike family setting which the proponents of S. 2053 are promising. But the proposed bill makes but a feeble and meaningless attempt to fix these most pressing problems of community based facilities which, because of the additional demand that it will create, are likely to become very much worse.

Because of the above reasons S. 2053 is not a realistic solution to the fiscal problems of Medicaid, but a naively wasteful, simplistic approach to a very complex issue which goes against the very purpose of Medicaid. It is likely to result in very substantial increase of costs and will cause untold harm to many. It deserves to be defeated!

You should know that because of these and other objections, the Association for Retarded Citizens of California (ARC-CA) passed two strongly worded resolutions against it's national organization's involvement in sponsoring this legislation and continues to be strongly opposed to S. 2053. I am aware that similar opposition throughout the Nation is also shared by many other ARC organizations.

Refrences:

1. S. Landesman-Dwyer: Living in the Community. Am. Journal of Mental Deficiency 1981, Vol. 86, No. 3, pp. 223-234.

2. Legislative Analyst State of California: The Phase-Out of the Developmental Disabilities Program at Patton State Hospital. January 1982.

3. C. R. Miller: Deinstitutionalization and Mortality Trends for the Profoundly Retarded. in C. C. Cleland & L. J. Talkington (Eds.) Research With Profoundly Retarded. Austin TX The Western Research Conference and the Brown Schools.

Edward A. Malone
Management Consultant

February 8, 1984

Mr. Roderick DeArment
Chief Counsel
Committee on Finance
U.S. Senate Room SD219
Washington, D.C. 20510

Dear Senator:

I am writing you concerning Se~~nate Bill #2053~~ entitled "The Community and Family Living Amendments of 1983" which was introduced in the Senate on November 4, 1983 by Senator John H. Chafee of Rhode Island. I consider this bill to be ill-conceived and one that should be cancelled or dropped.

I consider myself to be well qualified to comment on this bill. I have a son who is mentally retarded, and presently resides at Beverly Farm in Godfrey, Illinois. Ned has resided at Beverly Farm since 1966, a period of 18 years; they have been 18 great years for Ned and 18 years of confidence for our family. Beverly Farm is an outstanding facility, is owned by the parents/guardians of the residents there, is licensed as an intermediate care facility (ICF-MR) by the State of Illinois and provides exceptional accommodations with particular emphasis on tender loving care to each resident.

The care, activity and development in the least restrictive environment as furnished at Beverly Farm could not be duplicated for my son in a group home facility. I am not opposed to group homes as a community facility but to have a group home program as proposed in Senate Bill #2053 would be completely unacceptable to me and I believe to the majority of the parents of profound and severely retarded children.

I am not represented by any group other than the Beverly Farm parents group and the "Voice of the Retarded" group in Chicago. I desire that my opposition to Senate Bill #2053 be considered opposition of a parent with experience.

I recommend that Senate Bill #2053 in its entirety be cancelled or dropped and that my letter be entered as testimony in opposition to Senate Bill #2053.

Sincerely,

Edward A. Malone

Edward A. Malone
1126 Hunting Court
Palatine, IL 60067

EAM:am

PARENTS & FRIENDS VOLUNTEER ASSOCIATION
OF
Mt. Vernon Developmental Center, Inc.
P.O. Box 762 Mt. Vernon, Ohio 43050

WRITTEN TESTIMONY FOR THE RECORD - SENATE HEARINGS ON S2053

C.B.O. MEMORANDUM:

The C.B.O. Memorandum of December 8, 1983 by Diane Burnside, subjecting Senate Bill S2053, Community Based Living Arrangements, to a cost analysis can be described as being statistically and factually inaccurate even from the viewpoint of a layman.

First consideration must be paid to the outlay estimates as presented which are doubtful, at best. It must be assumed that such figures are projected both by the number of residents presently in M.R. institutions, and the alleged cost differential of these same residents in a community setting. It should be pointed out, however, that all cost comparisons to date have been conducted using mildly retarded persons as models in both settings. Research organizations have yet to produce studies of the severely handicapped retarded population's comparison costs in both environments because they do not exist. Residents of institutions selected for possible community placement are screened carefully for adaptable characteristics before placement. We must, therefore, discount the difference in cost theory on the basis of institutional per diems being exactly equal for a mildly involved resident as opposed to a profoundly involved one, requiring more intensive care, therapeutic and medical treatment.

By all means, we must question the outlay estimates when the fact that many thousands of people will be added to Medicaid rolls who are presently receiving family and other support. By virtue of the broad scope of S2053, the National Association for Retarded Citizens estimates one million people will be added who are not now receiving Medicaid.

The cost of deinstitutionalization estimates are rather paltry when one considers the start-up costs of one Medicaid-certified facility. It would be interesting to know the source of these estimates. According to S2053, the structure must not be unlike its surroundings; must conform to all local building codes; and must meet strict Medicaid standards as to square footage per resident; emergency facilities; emergency exits; furniture (quantity and quality); training of staff; rehabilitative and recreational programming; resident charting, planned diets, and proper medical procedures, to mention only a few. The figures, however, seem only to assume movement into non-certified homes.

In addition to the expense of Medicaid certification, there will be the age-old problem of finding a community in which the homes will be approved. Many of our Ohio communities have enacted moratoriums on group homes, regardless of size. In such cases, court proceedings may be necessary to test constitutionalities and litigation will add to the start-up costs.

The C.B.O. report makes many open-ended statements which are questionable, such as:

1. Projection - decline of institutionalized residents at a .017 rate due to death and placement.

   Statistical Fact - One (1) in five (5) babies born per year are mentally retarded, .2% requiring institution placement for various reasons.

   Question: Isn't the .017% a lower rate than the .2% admission rate?
2. Projection - Certain educational programs for institutionalized residents are paid by other sources, but will be picked up by this program.

   Statistical Fact - Many institutions provide on-grounds programs which are then a part of their per diem costs.

   Question: Is the added cost of these programs included in the deinstitutionalization cost projection, or will public education and local M.R. Boards be required to assume the responsibility?
3. Projection - Each state would select its own models of community living determining the cost/saving factor.

   Statistical Fact - Due to the absence of data comparing institutional versus community costs, community costs on a resident by resident basis may be higher.

   Question: It is constantly assumed there will be a savings in all cases. To what point do we retreat if the cost is greater overall?
4. Projection - No allowance was made for behavioral treatment of the residents placed in the community.

   Statistical Fact - According to a study by The Association for the Retarded in Minnesota, " unfortunately, some people who have been moved to small living arrangements have regressed. Small scale facilities do not cause good programs."

   Question: How does the possibility of regression impact the per diem figures? What is the ratio of progressive to regressive behavioral patterns?

The C.B.O. estimate, like S 2053, assumes "one size fits all" and reflects a study completed in haste and totally without foundation of statistically or technically accurate analysis. Observation of recent development by community providers would indicate that even 15-bed facilities are not cost effective, given the services that must be provided; therefore, 32, 48, and even 100 bed facilities have been newly constructed. S 2053 would effectively establish their demise some 15 years down the road and we view that as financially demoralizing.

GENERAL OVERVIEW of S2053 and ITS IMPACT

Despite its claims to "protect" the institutionalized M.R. population, S 2053 will, in effect, legislate deteriorating living conditions in institutions. The influx of Medicaid funds into institutions, and the necessity to meet ICF/MR standards, have made possible steady improvements in the surroundings and quality of life for all residents. In addition, for the first time, there exists a stability of funding never possible when this population was riding the roller coaster of shifting state political priorities.

Apparently Ohio is further advanced than many states in community development. At Mount Vernon Developmental Center there has been active placement in the community, with the only recidivism being necessitated by severe medical or behavioral needs. Our population already reflects only the most medically and/or behaviorally involved residents.

The State of Ohio has problems, however, with efforts to mandate wholesale deinstitutionalization. An example is Ohio's decision to close Orient Developmental Center and adapt the facility to a prison. Accordingly, Orient's budget monies were redirected to community development and, now that the Center's alternative placement is bogged down with approximately 300 residents not yet placed, money must be drawn from the remaining Centers' funding to operate the facility. This represents a serious deprivation for all concerned.

As parents, we protest the condescending attitude of the M.R. professionals who persist in "patting us on the head" as they assure us that our sons and daughters belong in the community despite their multihandicaps. Nonsense. This intellectual "philosophy" on the rights of the retarded was long overdue for many who can profit from life in the community; however, we had our family members in the community and sought placement in an environment where, overnight, they achieved a human dignity and security that was not and WILL NEVER BE available in the public sector. Only the larger facility can guarantee residents the built-in monitoring systems, Clients' Rights Advocate, and Security team which protect our family members who cannot protect themselves from abuse.

We who have failed at coping on a 24-hour basis, not only recognize the obvious benefits of three 8 hour shifts, but also understand the pressures contributing to the frequent turnover in group home staff. Unable to manage a family member's physical, medical, and behavioral needs in the community, parents view with concern anyone's ability to cope successfully in a group home situation. The longevity of group home operation is also a concern, as frequent closure is already evident. Again, the larger facility must be available as a support service.

No legislation from Washington will diminish the community's staring; nor will it banish the zoning moratoriums; or encourage the medical community to understand and treat the M.R. population with compassion. Given the medical and physical involvement of our population, Senator Chaffee's bill literally strips us of any notion of secure, lifetime care; older institutions fazed out in 10 years, newer large facilities in 15.

It is our understanding that there are alternative bills being drafted - one by the New Jersey Division of Advocacy for the Developmentally Disabled and one by the National Association of State Mental Retardation Program Directors. Both emphasize the need for a continuum of services and neither would remove federal assistance from larger facilities as long as standards are met and residents appropriately served. We heartily endorse both approaches and urge consideration of either of these bills as alternatives to S 2053.

STATEMENT
OF THE NATIONAL COUNCIL OF HEALTH CENTERS
TO THE
SUBCOMMITTEE ON HEALTH
COMMITTEE ON FINANCE
UNITED STATES SENATE

ON THE

COMMUNITY AND FAMILY LIVING AMENDMENTS ACT OF 1983
FEBRUARY 27, 1984

The National Council of Health Centers takes this opportunity to offer its views on S 2053, the Community and Family Living Amendments Act of 1983. The proposed legislation would phase out Medicaid funding for residential facilities serving more than six to nine severely disabled persons while entitling such individuals to receive a wide array of home and community-based services.

Members of the National Council are investor-owned multifacility nursing home corporations that own or manage approximately 2,000 nursing centers in 48 states and the District of Columbia. Our members also provide many other health-related services, such as home health, alcohol and drug rehabilitation programs, retirement communities, and hospice centers. In addition, National Council members operate many facilities that provide services to children and adults who suffer from mental retardation or psychiatric disorders. Based on the experience our members, we believe that the program proposed in S 2053 would be detrimental to the improvements in care for the developmentally disabled that have been achieved over the past several years.

We fully support the legislation's intent: "the full participation of severely disabled individuals in community and family life." Improving the lives of such Americans should, without question, be the goal of Congress, as it is the National Council's. But the provisions of S 2053 are based on arbitrary size limitations, and supported by questionable cost analyses and interpretations of major studies, relating to deinstitutionalization.

Recent national efforts to restructure care for the severely disabled have met with little success. The anti-institutional outcry of the 1970s and the "normalization" campaigns that followed were aimed at the deinstitutionalization of overcrowded large mental institutions.

The result was disastrous and tragic. Thousands of mentally ill persons flooded communities without the corresponding shift of adequate community services or resources. Many of these people, unable to live independently, were forced into substandard boarding homes or shelters for the homeless. Others were isolated in small homes uncared for and ignored or eventually forgotten. The message that emerged was that deinstitutionalization is good in theory, but without proper planning, research and community support, it has been badly executed. We believe that S 2053 would be an other example of such poor execution, and we urge the Senate Finance Health Subcommittee to oppose it.

The following are our specific concerns:

There is little evidence to support the argument that all mentally retarded individuals are better off living in small community-based settings. S 2035 would limit Medicaid payments to eligible individuals residing in a "community or family living facility" with a capacity no greater than three times "the number of persons in the average family household in the area in which the facility is located. . ." As the average family household in the United States generally runs between two and three, the maximum size of a community or family living facility would be six or nine individuals. The current literature offers no evidence to support the premise that independent living skills can be taught only in certain-sized facilities or that given the same individual care, developmentally disabled persons progress better in smaller than in larger settings.

A 1980 study, "On Size and the Quality of Residential Care: A Second Look" by George S. Baroff, reviewed several major analyses of size as a relevant factor in residential care practices in institutions. The author examined the two kinds of studies that pertain to size. One involves the relationship between size and the degree to which care practices are resident-oriented versus institution-oriented. The second considers actual resident adjustments in settings of different size. Neither instance showed a relationship between size and the degree to which care practices were resident- vs. institution-oriented.

Similarily, after analyzing data on clients in group homes of differing size (ranging from 6 to 20 residents), a research team at the University of Washington Child Development and Mental Retardation Center concluded that:

> ". . . group home size usually was not the most important factor. Variables such as geographic location of the home, heterogenity of the resident's background, and average age of the residents were typically more important than was the number of residents in determining patterns of eating, social behavior, organized activity and being unobservable."

Community placement is ideal for many developmentally disabled persons but not all. These individuals have varying and diverse needs. In addition to suffering from mental retardation, an individual might also, for example, be deaf, blind, epileptic and unable to speak or walk. Service needs may vary from vocational training and management skills to the intensive medical care and therapy services. Lower-functioning individuals are seldom accepted into community or family care homes. Incontinent and non-ambulatory clients require more than can be provided in a community setting. Others who are not accepted into the small community environment are people who may function in the severe to moderate range of retardation but have involved medical problems. Severely impaired individuals with cerebral palsy, uncontrolled seizure disorders, and/or sensory impairments are just a few examples. These people may not need the expensive and intensive care of the restricted environment of a state hospital, but neither is community placement appropriate for them. They are aptly cared for in an intermediate care facility for the mentally retarded (ICF/MR).

ICF/MRs also have two important advantages over smaller community facilities: a stress on socialization and staff longevity. Portland Residence, a ICF/MR in Minneapolis, MN, serves 100 residents. To give its clients experience with small groups, the facility is divided into eight living units. For socialization purposes, a resident has the opportunity to mingle within his or her unit or in other units. This flexibility in the setting allows an individual the stimulation of a variety of functioning levels. If a person in a group home has an active personality problem with others, that individual will likely leave the facility. At Portland Residence, however, there is an opportunity for residents to move within different levels of environment so that a client who has conflicts with others does not have to be removed from the system and feel that he or she has failed.

Staff longevity is an important element of many ICF/MRs. These facilities experience a very low burn-out or turnover rate because the staff works an 8 to 10-hour shift per day during a 40-hour week. These limited shifts keep the staff mentally and physically fresh while working with residents. This arrangement contrasts sharply with the high burn-out and high turnover rate in small community-based facilities where the staff live and work with the residents 24 hours a day. Further, many ICF/MRs hire only college graduates to work as direct care staff, thereby employing mature, disciplined people who are trained to think and work with the residents. Economies of scale and other efficiencies gained from their size allow ICF/MRs to offer the competitive salaries to attract such employees. This cannot be said of many small community facilities. Large ICF/MRs offer the residents an array of services: registered nurses, speech pathologists, speech clinician and education departments with teachers trained in special education, music therapy, and recreation therapy.

The evidence is quite clear. A continuum of programs and living alternatives are necessary to meet the many needs of the severely disabled. Often the placement most appropriate to that individual's needs is a large ICF/MR facility where the necessary professional staff and services are available.

The current literature offers no substantial evidence that small facilities are less expensive than larger facilities. Major studies indicate, at best, a weak relationship between size and costs. New York City's 1981 examination of community residence programs for individuals with severe and profound developmental disabilities found that the small and community-based residences studied reported higher per-client costs than the comparable adjusted average annual per-client cost for developmental centers in the metropolitan areas.

A 1976 study of community care facilities, "A Typology of Community Care Facilities and Differential Normalization Outcomes," by Edgar Butler and Ann

Bjaanes, concluded that there are substantial differences in utilization of community agencies, services and programs by facilities, and variations in normalization activities within facilities. The authors found that:

> "Larger facilities, by and large, utilize agencies, services and programs, and have more internal normalization activities and, thus, appear to be closer to the objective of normalization and developing social competence than smaller facilities."

A comparative cost study of public residential and community residential programs by the Research and Training Center in Mental Retardation at Texas Technological University revealed:

> "Based upon data collected in this survey, the costs of providing community-based residential services appear to be at least equal if not greater than those in public residential facilities."

The Health Care Financing Administration, in a January 1981 report, "Background and Future Directions," said:

> "There is little evidence that coverage of community-based and in-home services reduced total public expenditures in an open-ended fee-for-services system. Indeed most of the evidence is to the contrary. This is because expanded service benefits largely go to a new (additional) service population rather than substituting for nursing home care."

We agree with the National Association of State Mental Retardation Program Directors, Inc.'s argument that when some of the very studies cited by proponents of community-based services are examined, the relationship between facility size and cost is not nearly so clear as it may appear. "For example, a recent report by the New York State Commission of Quality of Care for the Mentally Retarded, 'Willowbrook: From Institution to the Community," points out that the average annual per-client cost of care in state-operated developmental centers in the New York City area were approximately 29 percent higher than the average client costs among the sampled community residences. The authors of the report, however, go on to note that:

> 'The average per client cost among apartment residences ($39,156) was actually $2,132 greater than the average per client cost among the developmental centers. And, more significantly, the average per client cost among state-operated apartment residences ($47,660) in the sample was nearly 29 percent greater than the average per client developmental center costs.' "

It is quite obvious that there are no definitive studies of the relationship between operating costs and size. The scattered evidence that is available is contradictory and subject to various interpretations. Smaller facilities are not necessarily cheaper. Programs with eight beds or fewer in Pennsylvania, New York and Michigan have revealed expenses that are two to three times the costs of ICF/MR care. The McComb-Oakland project in Michigan reports costs of $70 to $130 per day. Costs in New York have ranged from $95 to $155 a day. Most small facilities for the mentally retarded are reimbursed at $75 per day, many by at least $100 per day.

Most states provide a $65-to-70 per diem for ICF/MR care. For example, Portland Residence's daily rate is $60, $10 less than the state's payment for ICF/MR care. This large facility serving 100 persons also provides numerous services, i.e., speech pathology and behavior analysis, that otherwise are available in a small facility only through expensive contractual arrangements.

The quality of care for the severely disabled will suffer due to inadequate community support. As mentioned earlier, past national efforts to deinstitutionalize the mentally ill without proper community support have met with little success. No new law or regulation can guarantee that the necessary system of services will be in place in every community thoughout the United States. It is impossible. We are skeptical of the ability of governments -- federal, state and local -- to prevent "dumping" that has occurred in the past and may occur under S 2053.

We are particularly concerned with the problems the proposal would bring to states with large areas with sparse population. For example, Lakecrest Developmental Care Center is an Orem, UT 75 bed ICF/MR that provides services to adolescents with mild behavior problems and other mentally retarded individuals. The facility is currently at capacity and has a patient-admission area covering a 400-mile radius. The transfer of the facility's residents into the community would be disastrous due to the lack of community services. The population distribution is inadequate for the handling of the deinstitutionalzation of ICF/MR patients. With 50 percent of the population of Utah located around Salt Lake City, the rest is spread sparsely over the state. In three-fourths of the state's communities, the availability of services, physicians, speech and occupational therapists as well as psychologists and physicians is limited. In addition, travel time and actual

Medicaid dollars available would make S 2053 unrealistic except in the Salt Lake City area.

A study conducted by the University of Massachusetts on the status of health care for deinstitutionized, mentally retarded persons in that state found several disturbing factors. Current health systems are reluctantly responsive to the deinstitutionized. Care for the mentally retarded person is exceedingly complex and time-consuming for physicians, and the skills needed by a doctor to care for the mentally ill usually exceed those that he or she received during training. Most medical staff are ill-prepared or lack the knowledge to deal with the mentally retarded's health problems, and many physicians, dentists and nurses have problems dealing with people whose appearance or behavior is different and want to segregate them from other patients. In a similar vein, the Texas Technological University study found that:

> ". . . being in a group home does not automatically mean a better quality of life. Without the provision of training, opportunities for vocational and social activities and outside monitoring of programming, it is possible that a group home may become more sterile than that of a public residential facility."

S 2053 would unfairly restrict state flexibility in providing services for the severely disabled. The proposed legislation is oppressively prescriptive at a time when states need maximum flexibility in devoting shrinking funds and resources to care for the severely disabled. State institutions still will need to remain open to incur full fixed costs of operation as well as the marginal costs of caring for individuals who will remain institutionized because of their medical condition or the inability of the state to make a community placement. Further, S 2053 would force states to comply equally with statutory priorities not tailored to the current status of their efforts to deinstitutionize.

The increase in the number of program eligibles and program costs that would be imposed by the new legislation would be extremely difficult for the states to absorb, particularly in light of the Reagan Administration's efforts to further reduce the federal share of Medicaid.

The states have already moved consistently over the past 15 years to successfully reduce the total population of public institutions. That population has dropped by 37 percent over the last 11 years while the number of community residencies has increased by more than nine-fold over the same period.

The states, and not the federal government, should have prime responsibility for planning a continuum of services for severely disabled citizens. The federal government should be supportive, not pre-emptive. It should serve as a catalyst and supplement state efforts only as needed. Clearly, states will continue to include a varied number of institutional beds as part of that continuum of care.

Deinstitutionalization of the severely disabled is already available through home- and community-based waivers. Incentives for appropriate deinstitutionalization already exist under home- and community-based service waivers available under Section 1915(c) of the Medicaid law. At present more than 20 states have waivers for the mentally retarded, and other states are pending approval. These waivers increase the incentives for states to develop less costly alternatives to institutional care and to operate their facilities for the mentally retarded more efficiently.

Many community service packages for the developmentally disabled are more costly than institutional care, a fact that casts doubt on the savings assumptions included in the proposal. If community care is less expensive, it can be covered under present law and no statutory changes are necessary.

Summary

For the many reasons discussed, the National Council of Health Centers opposes S 2053. The National Council believes the program and support for the legislation is based on arbitrary size limitations and questionable cost analyses and interpretation of major studies relating to deinstitutionalization. S 2053 would jeopardize the improvements in care for the mentally retarded that have been achieved over the past several years. The National Council urges the Senate Finance Health Subcommittee to oppose S 2053.

TESTIMONY OF THE
NATIONAL FEDERATION OF LICENSED PRACTICAL NURSES, INC.

SUBMITTED TO THE
SENATE FINANCE COMMITTEE
SUBCOMMITTEE ON HEALTH

ON
THE COMMUNITY AND FAMILY LIVING
AMENDMENTS ACT OF 1983

MARCH 12, 1984

Mr. Chairman, the National Federation of Licensed Practical Nurses, Inc. (NFLPN) appreciates the opportunity to present its views regarding the inadequacies of the present Medicaid reimbursement system, and the future of health delivery to our Mentally Retarded and Developmentally Disabled (M.R.D.D.) citizens.

The NFLPN is the professional organization which represents this country's 750,000 licensed practical nurses (LPNs). As an organization whose members are dedicated to the delivery of high quality nursing health care, we have long been concerned with the lack of access to quality long-term health care which Medicaid provides to the economically disadvantaged. Unfortunately, today a number of problems plague the Federal-State partnership that provides care for patients with such disabilities as severe mental retardation, severe epilepsy, cerebral palsy and paralysis.

The vast majority of these, and other economically disadvantaged patients, receive long-term care in large, multi-purpose state institutions. Our experience tells us that these facilities are often too large and too inefficient to provide adequate care for a very diverse group of patients. In this type of facility, subtle differences between patients may be easily overlooked; consequently, the tendency is to tailor treatment to broad categories of patients rather than to the individual. As a result, sometimes patients do not receive the type of personal and individual nursing care which they need and deserve.

These large institutions hinder optimum habilitation in a second way. Despite the best of intentions, these facilities act as effective barriers between patients and the world. Our experience indicates that M.R.D.D. individuals, many of whom are only physically disabled, do not progress as well as they otherwise might when they are separated by miles and walls from their spouses, parents, friends and the general public. While such isolation can slow or even prevent proper treatment, constant interaction with others improves morale and habilitation.

The true tragedy of this situation lies not in the fact that such facilities exist, but in the fact that so many disabled individuals are forced, often with no regard for the appropriateness of treatment, to reside in them because they have no alternative. As the subcommittee knows, the cause of these problems is the institutional bias within the Medicaid system that forces states to rely so heavily upon large institutions. Their overreliance is apparent in the fact that of all money spent on Mentally Retarded Intermediate Care Facilities (MRICF), 82 percent is spent on larger, multi-purpose facilities, while a mere 4.5 percent is spent on public community and family care facilities.

Although some states, such as Rhode Island, have aggressively taken the lead in the shift to smaller community care homes, the present Medicaid system serves as a disincentive to change. It is presently the view of many health care professionals that the Federal government, as a partner with the states, must act if change is to occur. We believe, therefore, that S.2053 is an excellent proposal for change.

The effectiveness of S.2053 lies in the fact that it would attack the problems by eliminating their root cause. The inefficient and ineffective treatment of individuals in large public facilities would be alleviated by transferring these patients to smaller, individually tailored, closely supervised community and family care facilities. Such a transfer would be achieved by reversing the bias of Medicaid funding. In these small homes, men and women would have access to the individual treatment and attention that they require. We would expect these homes to establish regulations which would assure quality health care delivery.

Despite the claims of some critics, this proposal would not force all patients to fit into a predetermined, inflexible mild, or force patients to reside in a community setting regardless of the care they need. It is our opinion that section 1918(b)(1) would require care that "is not available at community or family living facility" in their home state. Thus, this proposal would make it financially possible for most patients to transfer to community living settings.

For those many men and women who would reside in a community or family setting, the benefits would be great and immediate. First, the ability of a disabled individual to live with or near a spouse, parent or loved one is an invaluable benefit. Secondly, these people would be allowed the dignity to care for themselves. LPNs quickly learn that patients progress most rapidly when they are treated as adults and as individuals. This proposal seeks to provide a fiscal mechanism that would allow disabled men and women to find dignity through independent living.

Although the NFLPN enthusiastically endorses S.2053, we do offer one suggestion for consideration. We encourage the subcommittee to include a provision that would reimburse the states for the training mandated by the bill. While we applaud the realization that such a mandate is necessary, we are concerned that state funding will not be adequate to provide the necessary training and retraining. If such a provision is included, S.2053 will serve to greatly improve the way this country provides for its disabled citizens.

National Mental Health Association
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STATEMENT PRESENTED TO

COMMITTEE ON FINANCE
UNITED STATES SENATE
WASHINGTON, D.C. 20510

CONCERNING S 2053
The Community and Family Living Amendments Act of 1983

BY

Richard C. Surles
Director of Mental Health & Mental Retardation, City of
Philadelphia and Member Public Policy Committee, NMHA

for the

NATIONAL MENTAL HEALTH ASSOCIATION

March 1984

My name is Richard C. Surles, and I am a member of the National Mental Health Association's public policy committee as well as Director of Mental Health and Mental Retardation Services for the City of Philadelphia. Prior to 1983 I was Commissioner of Mental Health and Mental Retardation in the state of Vermont.

My statement today is presented on behalf of the National Mental Health Association (NMHA), a voluntary citizen organization, representing approximately one million consumers and citizens interested in the treatment and prevention of mental illness and the promotion of mental health.

NMHA fully supports the concept of S 2053 -- i.e. that mentally disabled individuals should be cared for in the least restrictive setting, and that long term institutional care is no longer appropriate for most of this population. S 2053 primarily addresses the needs of mentally retarded individuals, although it also would cover those suffering from a mental illness, if they are under age 21 or over age 65.

My statement addresses the long term care needs of chronically mentally ill individuals, and how S2053 might better address those needs.

There are an estimated 1.7 to 2.4 million people living in institutional and community settings who, by virtue of their diagnosis, duration of illness and resultant disability, may be termed chronically mentally ill. Many of these people are inappropriately placed in institutions such as public mental hospitals and nursing homes, many live in substandard or inappropriate housing and many are homeless. Most of these people are missing one or more of the basic life supports necessary to a satisfactory quality of life.

Over the past two decades, it has been convincingly demonstrated that people with chronic mental illness can become more productive members of society if they have appropriate community living arrangements linked to rehabilitation and support services. Thousands of people currently in hospitals or nursing homes could function more independently in psychosocial programs, group homes, family foster care or supportive apartments if adequate numbers of such programs were available--at a total cost to the taxpayers that would be less than the costs of current arrangements, according to a report issued in February 1983 by the Departments of Health and Human Services and of Housing and Urban Development on *FederalEfforts to Respond to the Shelter and Basic Living Needs of Chronically Mentally Ill Individuals*,

What is needed is a continium of residential options for this population, ranging from hospitals to nursing homes, to group homes, to foster care, to shared apartments, to independent living. No single residential option can meet the needs of all the population.

Current problems in meeting the shelter and basic living needs of chronically mentally ill individuals stem from a number of causes, not the least of which are instances of localized shortages of housing affordable by low-income people and the stigma against people with mental health problems. In addition, however, it has become increasingly clear that there are major problems related to funding patterns, unclear or antithetical legislation, eligibility determination factors, planning and coordinating factors, and program accessibility. The outcome is overuse of hospitals and nursing homes, the use of substandard community shelter settings, and the shortage of supervised, appropriate community arrangements.

Chronically mentally ill citizens are not now adequately served under Medicaid, and yet many of them are among the truly needy, leading only a marginal existence and falling within the lowest socioeconomic strata of society.

The current Medicaid program is structured in such a way that, for the mentally ill, it emphasizes institutional care for those who may not need it, and encourages (even in non-institutional settings) more intensive care than is often warranted. In this respect, the priority given to institutional services by Medicaid is similar for mentally retarded and mentally ill persons. However, in one important respect, Medicaid coverage for these two populations is very dissimilar. Medicaid has no provision to cover intermediate care facility services for the mentally ill and specifically excludes inpatient care in a psychiatric hospital for those between the ages of 21 and 64

With the enactment of the Medicaid Home and Community Care Waiver in 1981, states were permitted to substitute community care for institutional care when community treatment would be more appropriate, and also less expensive. However, in developing a waiver request for Vermont (and Vermont was one of the first state to have a waiver which included services for the mentally ill approved by the Health Care Financing Administration) I found that it was very difficult to use the waiver authority to improve services for the mentally ill. This is because the only "institutional" services which may be offset against community care costs for the mentally ill, are services provided in psychiatric institutions for those under 21 and over 64.

Thus currently, Medicaid-eligible mentally ill individuals have a limited range of community services available to them, and severe restrictions on long-term psychiatric inpatient care if they are between the ages of 21 and 64. On the other hand, if persons are served in general hospitals then Medicaid will pay for acute care, thus encouraging the use of episodic acute care.

The problems in providing appropriate treatment to the mentally ill are many and the need for a national reorientation to care is critical. It is on these problems of appropriate care that I want to focus today in the context of S 2053.

S 2053 describes in some detail the types of services that would be available for funding for disabled people or, in other words, the services that would be considered to be medically appropriate by the Federal Medicaid program if S 2053 were enacted. These services include those now provided to mentally retarded persons residing in an intermediate care facility (ICF-MR), those services available under the Medicaid waiver program (case management, homemaker/home health aide services, personal care services, adult day health care, habilitation services, respite care and other services as approved by the Department of Health and Human Services), comprehensive services for independent living and specialized vocational services which enhance the independence, productivity and community integration of severely disabled individuals.

S 2053 uses the same definition of "developmental disability" that is found in the Federal Developmental Disabilities Act, and therefore covers the chronically mentally ill. It is appropriate for the chronically mentally ill to be included within this definition since the types of services they require and their problems in adjusting to community living parallel those of other disabled individuals. However, mentally ill individuals, unlike those with mental retardation, may need periodic in patient psychiatric care and the total duration of such care is unpredictable. Thus, it is important that S2053 not delete any current Medicaid institutional coverage for mentally ill persons under age 21 or over age 64.

We understand that S2053 is not intended to limit this institutional coverage for the mentally ill, but believe the bill needs to be amended to clarify this. Currently, section 1918 prohibits institutional services to all those covered under the bill. Mentally ill persons under age 21 and over age 64 should be excluded from this provision, so that they remain eligible for all currently covered mental health services.

The inadequate coverage of mental health services under current Medicaid law is a major problem. It results, in part from Federal restrictions, and in part from many states not opting to fully cover such services. As a result there is a lack of Medicaid institutional dollars to transfer into community services, as well as a serious and critical shortage of such community services. This is why I had such difficulty designing a Medicaid waiver program for Vermont and why so few states have even tried to apply for a Medicaid waiver which covers this population.

The most critically needed reform to Medicaid for mentally ill persons is expansion of Medicaid coverage for the less intensive services which are provided in the community and designed to prevent institutionalization. These services include especially: case management, psychosocial rehabilitation, residential programs, assistance with housing and other services defined in S 2053, and in the Medicaid waiver authority.

As a first step towards this end, NMHA urges the Committee to amend S 2053 so as to add a new provision amending Section 1519 of Medicaid (the Medicaid waiver) so as to enhance the opportunity for mentally ill persons to be included within the existing waiver program. This requires looking at the "institutional" services which, under the waiver, are to be replaced with community services in a slightly different way. For instance, states cannot now count as institutional services under the waiver, inpatient acute care provided in general hospitals. Also, some of the services provided on an outpatient basis are more intensive (and less cost-effective) than alternative community support services which are not now eligible for Medicaid reimbursement. Thus, partial hospitalization might be appropriately replaced with a psycho-social day program for a given patient. Intensive outpatient therapy might be replaced with case management to assist the patient with a whole range of problems which are significantly effecting his/her mental health and so on.

We thus propose that the Medicaid waiver authority be amended to specifically allow states to receive Medicaid reimbursement for community alternatives now described in under Section 1915 when these services are furnished to individuals diagnosed as having a mental illness and whose condition is severe and persistent, but for whom long-term skilled or semi-skilled nursing care is inappropriate, and for whom it is determined that a reduction of the disabling effects of this serious mental illness can best be accomplished in a non-institutional setting. These community services would be provided to individuals who might otherwise require services furnished on an inpatient basis by a general hospital, services provided on an outpatient basis by a general hospital, by a community mental health center or other clinic or private practitioner, or partial hospitalization services provided by a hospital or other provider.

States participating in the waiver should be required to promulgate regulations which will ensure that patients have a goal-oriented treatment plan, which will integrate clinical services and community support services, provide for continuity of services, and set standards for licensure of community facilities for mentally ill persons.

We further suggest that these home and community services funded through the Medicaid waiver for the mentally ill be paid for by the federal government at a higher rate than is allowable for institutional and other inpatient care. Specifically, the match for community services should be 5% higher than for institutional or hospital services. This will give states a positive fiscal incentive to develop community-based alternatives for those at risk of more intensive care.

While such a higher rate might appear illogical during a period of such federal fiscal constriction, we suggest that such provisions are cost effective. For example, in Philadelphia, inpatient mental health care in a general hospital now runs about $500 per day; community programs are significantly less expensive. Thus the use of community services is much less costly and much more effective than continuous admissions and re-admissions for inpatient acute care. Moreover, in keeping with the waiver concept, an overall cap on expenditure can be establiished to prevent run away cost from over subscription. Unless incentives are provided to states, however, people experiencing episodes of mental illness will continue to stay in hospitals because there is no where else to place them, and Federal funds will continue to encourage the utilization of the most expensive options for treatment.

Also, we are experiencing serious problems with the manner in which Pennsylvania has implemented Medicaid restrictions on public patients. Some hospital administrators are denying Medicaid patients who have no fixed address admission to the hospital, because when the patients are ready to be released there will be no place for them to go. If they fail to place a patient, the State medical assistance authority will deny the hospital public assistance for the inpatient care.

These changes are needed now more than ever as evidence grows that Medicaid budget pressures are causing states to single out services for the mentally ill for cutbacks and restrictions.

Our proposal for changing the Medicaid waiver is designed primarily to address the community-care needs of chronically mentally ill adults. S2053 also authorizes a range of community services for children under 21 and older adults over 64, if they meet the definition of disability in this bill. I want to emphasize that NMHA fully supports the inclusion of these individuals under S 2053. The services defined in the bill are exactly those needed by seriously and chronically mentally ill people and S 2053 represents a major and highly significant change in the Medicaid program's structure. I would like to specifically point out the importance of covering pre-vocational services. Day habilitation services which include task-oriented activities intended to help participating clients to acquire the social and job-related skills that are prerequisites to entry into a vocational training program are essential if chronically mentally ill people are to benefit from services furnished through rehabilitation programs. Currently, the chronically mentally ill are seriously underrepresented in the vocational rehabilitation system, primarily because they are not 'vocationally feasible' under the VR system's definition.

Another excellent provision in S2053 which I would like to strongly endorse is the fact that all those whose disability had its onset before age 50 would be covered. The DD Act definition limits services to those whose disability had its onset before age 21. Yet many chronically mentally ill people first show signs of their illness after the age of 21. Thus the age of onset in this bill is a significant provision for the chronically mentally ill, and we urge that it be retained.

There is one other amendment which NMHA would like to propose with respect to coverage for mentally ill persons under S 2053. As now written, someone who is 20 years old and diagnosed as schizophrenic when this bill is enacted would be eligible for a wide range of community services, which could enable him or her to live in a group home in the community, to receive vocational services designed to eventually enable him/her to hold a job, attend a psychosocial day program to assist with his/her independent living skills and receive medical treatment. What happens under S2053 when that same individual turns 21 a year later? There is no automatic coverage for any of these services. Indeed if he/she lives in a state which has failed to cover clinic services, and which has not applied for a waiver such an individual may find the only Medicaid services available are inpatient and outpatient general hospital treatment and physician services. Such a drastic cutback in supportive health-related services will quite certainly cause many chronically mentally ill people to suffer serious relapses and their potential to become independent and possibly productively employed citizens will be lost.

While our proposals to amend the Medicaid waiver would, in a substantial way, improve Medicaid coverage of health-related community services, S 2053 would cover additional services and because the waiver authority is optional, some states may not apply for a waiver for the mentally ill. There are also restrictions placed by HCFA on those states which do apply, and the rigidity of the formula used to calculate costs has already restricted the use of the waiver authority.

Thus, coverage under S 2053 is a significant improvement over the waiver authority, even though the waiver amendment recommended here is a significant improvement over current law.

We are therefore concerned about those mentally ill young people covered when S2053 is enacted, but who would lose that eligibility as they turn 21. NMHA urges the Committee to amend S 2053 so as to raise the age of cut-off from 21 to 22 a year after enactment, and by one year each year thereafter so that those initially eligible for a full range of family and community services retain that eligibility as they grow older.

In conclusion, we recommend:

> *That S 2053 be amended to clarify that institutional services for mentally ill individuals will continue to be reimburseable under Medicaid;
>
> *That S 2053 be amended to include language which amends Section 1915 of Medicaid so as to allow for appropriate reimbursement for home and community based services for chronically mentally ill individuals;
>
> *That the age of onset under the definition of eligibility used in S 2053 remain as age 50;
>
> *That the services defined in S 2053 as reimburseable under Medicaid not be changed, and particularly that pre-vocational services be retained;
>
> *That children and youth who are under age 21 when this bill is enacted, and who suffer from a serious and chronic mental illness, retain their eligibility for community services as defined in this bill as they grow older (i.e. that the lower age limit under Section 1918 (h) be raised by one year each year).

With the changes suggested above, NMHA endorses S 2053 and urges its adoption by the Congress.

Our proposals to amend S 2053 would mean that chronically mentally ill people have available to them a range of community care alternatives which are, for the most part, already available to other disabled people. Care for chronically mentally ill individuals has been a public responsibility for over a century. It still is a public responsibility, even though many chronically mentally ill people are no longer locked away in large remote institutions. Medicaid is the single most important funding stream for health-related services to this population, and for too long the mentally ill have been denied adequate access to the most appropriate and cost-effective services under Medicaid.

We urge the Committee to make the changes suggested above, and then to enact S 2053 as soon as possible.

COMMENTS ON S. 2053

--Submitted by--

Parents Association of Northwest Louisiana State School

The Parents Association of Northwest Louisiana State School has gone on record as strenuously opposing the Community and Family Living Amendments of 1983 (S. 2053), as introduced by Senator John Chafee. Our opposition stems from the fact that S. 2053 is based upon a radical "anti-institution" philosophy which runs contrary to research findings reported in the scientific literature. For example:

- A core assumption underlying the legislation seems to be that facility size per se is a major determinant of program quality, and that small residences are thus inherently superior to larger ones. Available research data does not support this premise. Placing a ceiling upon the size of facilities eligible for Title XIX funding is thus a highly arbitrary requirement that simply reflects a subjective bias against larger, multi-purpose residential programs.

- The proposed legislation also seems to presuppose that placement in a small community-based residential facility will, in and of itself, result in greater developmental growth and a superior quality of life than would accrue to mentally retarded persons in an institutional setting. Here again, this contention is not supported by existing research findings.

"If you stand at all, stand tall"

- It is frequently argued that community-based care is less expensive than institutional programming. However, even a cursory examination of the "studies" commonly cited to support this stance reveals that they involve highly specious comparisons, i.e., while the institutional costs reported inevitably include the full spectrum of services offered by the facility, cost data from the community are ordinarily limited to housing, food and live-in staff, excluding the cost of providing the full spectrum of needed programs for clients. The studies which have taken into account the monies needed for programs in the community have usually revealed that the cost of community placement does not differ significantly from the cost of institutional care and is, in some instances, more expensive.

- The Chafee legislation seems to ignore the significant differences between current institutional populations and those retarded people who are being successfully served in the community. The data make it clear that the overwhelming majority of residents of public institutions are severely and profoundly retarded (e.g., some 57% have IQs of 20 and below), have a high rate of concomitant physical handicaps, are highly dependent on others for assistance and support (e.g., some 60% cannot dress without assistance, 55% cannot understand the spoken word, and 43% are not toilet trained), and many require intensive medical life support measures. This population contrasts sharply with the markedly less handicapped persons who are typically served in community residences.

"If you stand at all, stand tall"

- The proposed legislation would, in effect, disenfranchise parents in terms of making decisions concerning the type of placement that would best meet their child's needs. It ignores the findings of several studies indicating parental satisfaction with institutional care and strong parental objections to transferring their offspring to the community.

It is our belief that major social policy decisions such as those proposed in S. 2053 should be based upon a careful scrutiny of available empirical data. We thus urge that the Senate Finance Committee's Subcommittee on Health solicit testimony from recognized authorities in the mental retardation research community. Specifically, we suggest that you seek input from Dr. Norman R. Ellis of the University of Alabama and from Dr. Carl Haywood of George Peabody College for Teachers in Nashville, Tennessee. Dr. Ellis is probably the world's foremost authority in the field of mental retardation research, and has made extensive contributions to the scientific literature (e.g., he is editor of the Handbook of Mental Deficiency, Psychological Theory and Research and also edits the International Review of Research in Mental Retardation, a series which currently includes 11 volumes). Dr. Haywood is also a leader in the area of mental retardation research, and recently served as president of the American Association on Mental Deficiency. We view this type of expert testimony as particularly important in light of the alarming volume of emotionally laden hyperbole and scientifically unsubstantiated contentions which we have observed in many of the written and oral presentations supporting S. 2053.

"If you stand at all, stand tall"

While opposing S. 2053, the Parents Association of Northwest Louisiana State School clearly recognizes the fact that an individual's service needs may differ at various stages of his or her life. We thus strongly endorse the development of a wide array of service options, including both institutional and community-based programs.

Submitted By:

Tommy Head, President
Parents Association of Northwest
Louisiana State School
Bossier City, Louisiana

"If you stand at all, stand tall"

Milwaukee, Wisconsin
February 20, 1984

Mr. Roderick De Arment
Chief Counsel and Staff Director
Committee on Finance
U.S. Senate, Room SD 219
Washington, D.C. 20510

Dear Mr. De Arment:

I wish to register my opposition to Senate Bill 2053, the so called, "Community and Family Living Amendments of 1983" for the following reasons.

1) Having failed to obtain a wide array of "community based" services under legislation on the books, the National Association for Retarded Citizens (ARC-US) is now attempting to obtain these services through Title 19 of the Social Security Act, by defining them as "medical assistance". (See U.S. Code, Title 42, "Developmental Disabilities Services Act") (esp. Subchapter I, par. 6001, "Definitions".)

2) Moreover, the ARC-US is attempting to delude the members of the Senate Finance Committee by creating a strong "diversionary issue", namely, the so called "redirecting" of federal medicaid funds from "institutions" to "family scale" facilities. They are hoping that, by "compromising" and dropping this feature out of the bill, they might obtain their real objective, as stated above.

3) The term "severely disabled individual", as defined in S 2053, is basically functional, not medical. It is so that practically every handicapped person in the U.S. would be covered under it. The new entitlements to "medical assistance" under

the costs of this bill would be staggering, far more than ARC-US is leading people to believe.

4) *If the bill is enacted, it would provide a "catch 22" for the states.* In effect, the states would have to either sign an "implementation agreement", which would create a vast network of "community and family living facilities" (including the *natural homes* of literally thousands of retarded individuals *not* currently in "institutions" but residing at home), or, *refuse to sign such an agreement*, with its huge financial commitment, and find that literally thousands of their handicapped citizens now residing in state institutions, private homes and hospitals operated by religious groups, nursing homes and other residential facilities would *lose their entitlements* under Title 19 of the Social Security Act. The real meaning of "redirecting the funds" means, in effect, *removing the entitlement* of people so housed, unless they are arbitrarily placed in what the ARC-US chooses to call "living, family scale" facilities.

5) My final point is a question: How come that a national association, presenting itself to the public as the advocate of *all* retarded citizens, and expecting political and financial support on this basis, contrives a bill, the net effect of which is to deny ~~the~~ medical assistance to thousands of mentally retarded citizens, unless they are "transferred" or "discharged" to a facility

which has, as its ordinary and basic requirement that the number of "beds" contained therein shall "not exceed the product obtained by multiplying by three the number of individuals in an average family household"? Is such an organization worthy of public support? I think not

Sincerely,

George L. O'Donnell
4961 N. Woodruff Ave.
Milwaukee, Wisconsin 53217

P.S. I am working on a detailed, annotated article, wherein I plan to lay before the public eye all of the intricacies of this sordid proposal, and let them judge for themselves

PAIR
PARENTS & ASSOCIATES OF THE
INSTITUTIONALIZED RETARDED
OF VIRGINIA

March 4, 1984
9000 Orange Hunt Lane
Annandale, VA 22003

Mr. Roderick A. Dearment
Chief Counsel
Senate Committee of Finance
SD 219
Dirkson Office Building
Washington, D.C. 20510

Reference S2053

Dear Mr. Dearment,

I am writing on behalf of the members of the Parents and Associates of the Institutionalized Retarded (PAIR) of Virginia, to express our strong opposition to the provisions of Senate Bill 2053, "The Community and Family Living Amendments Act of 1983." In your February 17 reply to PAIR President Mr. Bobby Tuck's letter of February 6, you advised that it would not be possible for PAIR to testify at the recent hearing, but that written testimony would be accepted. Mr. Tuck has requested that I provide that testimony.

PAIR is comprised of representatives of the five institutions for the mentally retarded operated by the Commonwealth of Virginia. Briefly stated, there are several key points we wish to make:

o We fully support community programs for those individuals who would be best served in the community.

o While we feel strongly that many retarded citizens are best served in the community (e.g., a group home), we do not support the notion that every retarded person is in this category. Approximately 76% of the residents of state-operated facilities are profoundly or severely retarded. Many of these individuals require special care that cannot be offered in the community in an effective and efficient manner. We are also concerned that the potential for abuse of such individuals is greater in community facilities; the public has much better visibility over institutional programs.

o The conventional wisdom that it is less expensive to care for the retarded in community homes is simply not proving true in the case of the severely and profoundly retarded. Experience of the Falls Church Community Service Board in Northern Virginia, for example, is proving that the costs of providing quality care in the community setting will be staggering compared to the cost of providing the same programs in the institutional environment.

o Being in an institution does not preclude community involvement if the right programs are provided. The excellent cooperation which exists between some institutions and the local community suggest that some institutionalized retarded may actually have better access to the "community" than those who are isolated at home or in some group homes.

o The quality of programs is not related to the size of the facility providing the care; it is based on the funding and other support provided the program and the quality of the staff. We recognize that there exist institutions with poor programs and facilities, and encourage efforts to improve those situations; we also recognize that there are community settings with poor programs.

In summary, Mr. Dearment, we recognize and appreciate the concern of the Senate over the welfare of the retarded. We only hope that any legislation on behalf of the retarded will recognize that there is no one solution which is best for everyone; we must retain the flexibility offered under the present system which provides the mode of care and development which is most appropriate to the needs of the individual.

Sincerely,

Bob Dupwe
Member, PAIR

7 Fury Drive
Selden, New York 11784
March 6, 1984

Congress of the United States
U. S. Senate
Finance Committee
Health Subcommittee

Hearing: February 27, 1984
S. 2053; Community and Family Living Amendments
Act of 1983

Testimony: Roy and Arleen Probeyahn
7 Fury Drive
Selden, N. Y. 11784

We attach our testimony to our State Legislature as part of this record for background and orientation purposes.

As to the proposed legislation; we generally favor the concept that severely disabled individuals are entitled as a matter of right to a free appropriate continuum of services regardless of age based on the needs of the individual in the least restrictive environment.

We favor deinstitutionalization but perceive that those families in the community with severely disabled individuals at home have been clearly discriminated against in the past to deinstitutionalize. More needs to be done to equalize the support of both segments of the population.

However, we do not favor any dramatic shift that will return those in the institutions to warehousing conditions again, in order to correct the inequities now being perpetrated on us in the community. There is room and enough resources to commit to equal support of these minorities who are separated only by their housing environment but whose needs otherwise are essentially the same.

We support this legislation if amended to reflect a balanced position to support all those with severely disabling conditions that fosters the placement of housing for them in the community but does not unrealistically attempt to impose rapid changes by inappropriate funding shifts.

Cordially,

Roy + Arleen Probeyahn
NR

Roy Probeyahn
Arleen Probeyahn

RP/mr

Position Paper: The Tragedy of Aging Out
Roy & Arleen Probeyahn, 7 Fury Drive, Selden, NY 11784
On Behalf of: Roy, Jr, Mike & Glenn & Their Peers
March 6, 1984 - Day in Albany

My wife Arleen and I are the parents of three autistic young men, Roy, Jr., Mike and Glenn, ages 21, 20 and 16. We love them very deeply and have raised them in our home together from birth 'til this very day. We hope to be able to continue as a united family in our natural home environment for many years to come. We are opposed to the human warehousing of disabled people in institutions.

The boys' functioning level can best be described as profound to severe. Michael is most severely handicapped being essentially non-verbal and not becoming toilet-trained until he was 13 years old. By the way, it took us five years to get, then Suffolk State, to do that for Michael as an out patient resident there, as we refused to commit him. We knew he was not incapable but was actively resisting it and 24 hour, round the clock efforts were needed, and - we were right! He still has occasional lapses but he is trained. Roy is less disabled but does not engage in conversation although verbal. Our youngest Glenn is the least affected but has a very fragile emotional base and has toilet accidents regularly, but he is quite verbal.

Eighteen years ago the local school district could not deal with Roy nor later Mike and we turned to AHRC for help in their education. Then Suffolk Center for Emotionally Disturbed Children began servicing clients and they went there and ultimately to Suffolk BOCES III Autistic

Program at James E. Allen Learning Center, Melville. Glenn followed much the same track. Roy, as you may have noted, aged out this year and is back at Suffolk Center Adult Day Treatment.

Arleen and I do not believe in "letting George do it" either and saw as part of our mission in life, not only the care, and feeding of our sons, but additionally the work of advocates for them and all other handicapped children.

As our listed affiliations, attached, will show we volunteered as active members of numerous private and public organizations for the betterment of the quality of life of handicapped students. We took leadership roles, sometimes actually formulating the organization, we worked on committees, did fund raising, supported legislation, educating ourselves constantly so as to keep abreast and knowledgeable. We were successful! We and the parents and educators and friends we joined with can proudly bask in the light of what has been achieved for the improvement of the quality of life for all disabled children and young people under the age of 21 in the educational and social sphere.

To be sure much remains to be done, diplomas for the disabled, community based placement in local school district programs for even profoundly and severely disabled students, addressing of the 30 some odd state non compliance areas vis a vis PL94-142 etc.

Our major concern with the State Department of Education regulations are that they cease to apply to students over 21 years of age. Only now are our children growing and blossoming and beginning to fulfill our dreams for them in free appropriate educational settings. I must tell you that only in the last three years do I truly believe our son's I.E.P.s have been realized.

Arleen and I, however, have made asses out of ourselves and others, because, that's what happens when you assume. We assumed, that while we worked so hard for the younger ones, the children someone was doing the necessary for the adults. And it seems, most particularly for the aging out adults who have lived in the community, we assumed wrongly. Things are worse now for aging out adults than when we began in the educational sector for children 18 years ago.

While we certainly empathize with those who have suffered the indignities of human warehousing and by no means belittle their plight, I am addressing today the concerns of parents like my wife and I who were able to cope with their handicapped children at home - thank God - given the promise of help and a free appropriate education from the society at large through the public sector. We struggled for years to have these rights guaranteed into law only seven short years ago.

And yet, my oldest this year and my second next year; Roy and Mike, having reached the magical, mystical age of all knowledge - 21 - will or have fallen into the abyss of day treatment because the law says they can no longer benefit from an education.

Have we been sold a bill of goods? Is that all there is? Is this the ultimate Catch 22? We've coped, we've loved them, fought for them and their peers for twenty years, and what's our reward? -

More scratching and foraging and work and advocacy for our "aging out" children's appropriate care, training and housing.

You've heard of students' "aging out", what about parent "burn out". When can we rest; assured that the full life of our children, to whatever extent it can reach is insured. The puzzle must be finished and all the pieces filled in - our work is not yet done. We've been led down the garden path into a bed of thorns.

Were we wrong not to have placed them in institutions or residential care? Had we done so we would have freed ourselves of the burdens of dealing with their exceptional needs in our home; freed ourselves of the financial burden of their upbringing which included almost catastrophic medical expenses. They would receive more time under State Education funding as students, they would have first dibs on hostel beds, and day care placement, under your plan. Not to mention a savings of about $50,000 a year in cost to the state for institutional care times three times 21 years which comes to about $3,000.000.

Of course, there are some who play the numbers game who might say that we cost everyone money.

I have little doubt that Mike and Glenn who suffered severe pulmonary problems as children and Roy who almost succumbed to a rare disease would not have lived to adulthood if left to the tender mercies of the then, institutional care mechanism in place, had we chosen that for them. A similar fate, suffered by their peers by the thousands, I'm afraid, who had no such choice. Since we obtained for them the best medical care available they are alive and well today and have a right to live their lives to the fullest as do we all.

We personally know, in our suburban/rural community numerous single parents in their seventies caring for 30 and 40 year old adult handicapped persons, many of them married who have been in the community all their lives.

Do the nay sayers fail to see the growing crisis? How inhumane and unfair if these people end up in institutions or on the streets.

A subtle but dramatic shift has occurred in the last seven years. Our society admits a responsibility for profoundly and severely developmentally disabled adults from the cradle to the grave while institutionalized prior to that time. This warehoused all people whose handicaps made them significantly different from their "normal" peers and had full support from society which grew out of the general populace's fear and prejudice through ignorance of these disabled persons.

Now, those kept in the community, are not thought of as having a right to live in a society; which provides them necessary services under the guarantee of law after reaching age 21, simply because state education funding stops, but as merely having an understandable but somewhat unrealistic expectation that some services may be available. These people have, as a matter of human and civil right, entitlement to a continuum of appropriate services which must be guaranteed in law with due process safeguards, based on the needs of each individual.

We urge you to join us in this last frontier of civil and human rights, for a minority which is incapable of asserting their own rights, and unequivocally state your support for this concept.

We believe disabled people are entitled to live in the community and receive a free, appropriate public education and training regardless of age. They need to be taught how to compete in the real world of work, to become taxpaying, productive members of society in the employment marketplace. They belong in the community, in homes, churches, schools; at work and in places of recreation so the non-disabled can get to know them and not be afraid nor ignorant of them, nor prejudiced toward them; so that they themselves, can benefit from the exposure to the modeling behavior of normal healthy persons, more fortunate than they.

How many, thinking back, can say as children they ever saw or knew a severely disabled person. How many children and adults could answer differently today? It has not changed - and it must - for us to overcome.

These people are not criminals, nor freaks, not to be pitied, but rather to be accepted as they are; human beings, citizens of this great state and nation, who are the way they are through an accident of fate; through no fault of their own. They are not to be treated differently, warehoused together in residential care, schools and at work, hidden from their normal peers, denied diplomas upon graduation, segregated from society at large in every conceivable way. They do need a good faith commitment from the state to fund the public and private sector in a meaningful and consistent way so this can begin to happen.

We've tried to do our part, we take the boys shopping in the supermarket and other stores, to the movies, swimming at the beach, bowling, plays and to Church on Sunday in the hopes of making more people aware and accepting of them and it works.

We kept our sons at home because we love them and believe that is right. But, we thought there was a partnership with our government; that a continuum of services would exist. We thought wrong! Again! Where are the hostels and community residences for them to live as they approach and reach manhood? Where are the jobs or Day Training or prevocational programs to help them get those jobs?

There is not a continuum of services available for community clients. In Suffolk County there is no Day Training Module in place today. Not one application has been made in Brookhaven Town for a community residence in 15 months and the goals for beds set forth seems woefully inadequate. Not only are there losses of jobs in the institutions through attrition but there have been actual layoffs in the Community Services offices.

We applaud recommendations to commence census taking and centralization of service access and provision. It is a morass of bureaucracies we are faced with; O.M.R.D.D., Suffolk County Department of Social Services for medical and transportation, Office of Vocational Rehabilitation for training and on and on.

We are also troubled at what appears to be a mindset among the bureaucrats and service providers that day treatment is lifelong and day training and prevocational training - if it exists anywhere - is preparatory to sheltered employment and the latter is the ultimate expectation level. Our vision is that our constituents, our children and their disabled peers, no matter how severe their disability, should be trained towards competitive work and the necessary done to find and place and keep them in those jobs. If you only plan to build a hovel you'll never have a home.

The sheltered workshop, like the human warehouse is a bad idea whose time should be ending if not over.

It's goal should be to train itself out of existence, not to be an end in itself. We have worked and effected change in curricula where the boys have been educated; to lay that groundwork for the adult programs. But, that does not mean we should write off the existing clients. Let us begin to teach them meaningful work today and put them to work in the community of competitive employment tomorrow; sweeping, washing, delivering, photostating, folding, stacking, whatever work there is to be done, no matter how menial or simple. Please join us in that vision.

Where are the overnight respite services - not a day ward in a hospital with a TV on the wall - but a community residence designed to be flexible to take my Michael when we have a function to go to that Roy and Glenn would benefit from but not our dear Mike. What happens is we don't attend the event or leave them all home or hire a person to care for them while we're gone. Without this service, lord forbid we get sick together, and we have and we do and it's tough, let me tell you, to care for ourselves and them.

Is this Catch 22? - you've closed the institutions - but - not provided the community based services to help us and our children as we "age-out"?!

Have we wasted the money and time and effort of 18 years of education, all the state aid and local dollars spent, all the professional talent in drafting I.E.P.s and conferences and teaching and parent effort, that will be lost in the springboard down into post 21 services and programs.

In closing let me share with you, our greatest fear - that our children will outlive us - based on the level of services presently available we rather face the horrible, unthinkable grief of burying, our children than think of leaving them to the tender mercies of life in this place and time without us to insure their rights and dignity as human beings.

We hope you see us as reasonable, involved and concerned thinking people - if you do and you think about that statement all else is extraneous - please put that fear to rest, allow us the right to hope for as long and healthy life for our children as you do for yours.

AFFILIATIONS

1. Middle Country Central School District #11 - Special Education P.T.O. - Past President - Ten Terms
2. Selden Taxpayers Assoc., Inc. - Past President - Three Terms
3. James E. Allen Learning Center - P.T.C. - Past President - Two Terms
4. Suffolk Child Development Center - Parents Assoc. - Vice President
5. Middle Country Central School District #11 School Community Relations Committee - Charter Member - Vice President
6. Middle Country Central School District #11 Committee on the Handicapped - Parent/Child Advocate Member - 5 years
7. Middle Country Central School District #11 - Property Tax Relief Committee - Chairman
8. Town of Brookhaven Hostel Site Selection Committee - Current Member
9. Town of Brookhaven Advisory Committee on the Handicapped - Current Chairman
10. A.H.R.C. Mid-Island Auxiliary/Suffolk Chapter - Board of Directors
11. Both Recipients of the New York State Congress of P.T.A.'s Jenkins Memorial Award
12. Sensa (Nassau-Suffolk Special Education Alliance) - Charter Member
13. Members Nassau/Suffolk Chapter - National Society for Autistic Children
14. Member of Lt. Governor's Task Force on "Aging Out"

President's Council's Statement

regarding

Senate Bill S-2053

The President's Council of Parents Associations of Institutionalized Retarded Citizens (New Jersey) represents 8,000 families. The President's Council feels that Medicaid support should be made available to all eligible Retarded Citizens regardless of where they are living. Thus, Medicaid should be made available to all those eligible ones living with their families, group homes as well as institutions.

We realize that at the present Medicaid support may only be available to those living in institutions. We feel that this support should expanded to those eligible citizens living elsewhere. This portion of S-2053 is very good.

However, The President's Council vehemently objects to the provision of S-2053 having to do with the complete phasing out of long term care facilities (State Institutions). It has to be recognized that as the long care facilities become depopulated through the moving of the Retarded Citizens into the community, the less capable may have to remain in the institutions. There are also many non-ambulatory Retarded Citizens who can never expect to be moved into group homes, nor could community facilities other than hospitals or extended care facilities be able to furnish adequate care for such citizens.

Therefore, The President's Council feels that S-2053 in it's present form should be defeated and not be reintroduced until or unless it is revised to delete the portion having to do with the phasing out of long term care facilities. Only then would we consider S-2053 to be a viable instrument to permit the sharing of Medicaid support with all eligible Retarded Citizens in New Jersey.

STATEMENT

IN OPPOSITION TO

S2053 - COMMUNITY LIVING AMENDMENTS 1983

FINANCE COMMITTEE

SUBCOMMITTEE ON HEALTH

Senator Dave Durenberger, Chairman

March 13, 1984

PREPARED BY: Polly Spare, President
Pennsylvania League of Concerned
Families of Retarded Citizens, Inc.
P.O. Box 1133
Doylestown, Pa. 18901

Senator Durenberger, Members of the Committee:

I am the mother of two severely profoundly mentally retarded adults who reside in Pennsylvania state facilities. My daughter, Sandra, age 31, is a Pennhurst Class member who has been ordered by a Federal District Court into the community over our objections.

My presentation will address the realities of that mandate, its effect on the mentally retarded individuals involved, their families, and other citizens. My purpose is to provide you with hard facts for your consideration as you discuss Medicaid restructuring.

I present this position statement for The Pennsylvania League of Concerned Families of Retarded Citizens, Inc. I serve as President of this organization , as well as President of the Pennhurst Parents-Staff Association, Inc. The League, as we have come to be known, is a totally voluntary, nonprofit private organization, incorporated in Pennsylvania on September 10, 1981. We provide individual and group advocacy services, as well as information, to parents, legislators, and the public at large. We are all volunteers from professional and nonprofessional disciplines: law, public relations, accounting, business, just plain parents, etc. We serve persons who live in state facilities, private licensed facilities, and in the community. We provide no residential or day services. We receive no public monies. (See attachment #1)

In the past 27 months, Pennsylvania League has emerged as a long overdue reliable resource for information which is easily understood and easily accessable to the average family. We are not identified with normalization, deinstitutionalization, or the least restrictive alternative. Advocates of the "community only philosophy" have historically shown little or no interest in institutionalized persons and have offered little or no support for their families in times of crises.

In Pennsylvania, it was ARC-PA. who deliberately created a crisis of monumental proporations - the Haldeman vs Pennhurst litigation, a class action law suit designed to set a precident for eventual closure of all institutions. That fiasco remains unresolved after 10 years of appearances in Federal District Court, Third Circuit Court of Appeals, and three appearances before the U. S. Supreme Court. WE SEE S2053 AS AN ARC SPONSORED ALTERNATIVE TO THE UNSUCCESSFUL RESOLUTION OF THE PENNHURST CASE. Community advocates see the ICF/MR federal funds to state centers as a financial alternative to increasing state funding deficits. (See Costs, page 12) Our state centers care for our most debilitated population. These people will require as much, if not more, money for quality community care.

WHY DO WE OBJECT TO S2053?

This Bill appears to be a Medicaid restructuring proposal based on assumptions about care that could result in irreparable harm to very vulnerable people. The following list partially covers our concerns:

1. The prevailing atitude in this proposal is that all institutions are regressive. We disagree!
2. This Act assumes that all community placements are good just because they are smaller units. There is no empirical evidence, through present time to support such a contention.
3. S2053 arbitrarily establishes support for just one approach to care without recognition of the diverse needs of our mentally retarded population. It fallaciously assumes that all are equally capable of growth, development, and integration into the community. It does not allow for individuality or inability to conform.

4. It seems to ignore all positive congregate , as well as negative community living arrangement (CLA) experiences. Unfortunately, it is always the client who fails in the community - never the system. Our deinstitutionalized mentally retarded people are turning up in mental health facilities and on the streets.
5. It makes no allowance for parental or state preference in designing or establishing a system that best accommodates "needs" of the population to be served in a given geographic area. One program cannot possibly serve 50 states.
6. It does not seem to clearly establish that quality standards must apply to the community placement equally with the institution. What is good for one should apply to the other. It does order state centers to comply (with or without federal funding) to federal standards according to an implementation agreement with a penalty clause. Mentally retarded persons will be the losers in a noncompliance issue - budgets, programs, and support staff will be cut. Mentally retarded people are dependent on all three. Private community providers of small community facilities have proven that they cannot and will not operate without certain financial assurances.
7. It ignores the subject of medically involved persons who require behavior controlling medication. Our Pennsylvania CLAs do not employ nurses to dispence medications. The community is meant to be normalizing - it is not a medical model. (See "Case Histories", page 8)
8. S2053 assumes that all people can be assimilated into the general population. Present experience with the court ordered Pennhurst dispersal clearly indicates the opposite. Our people are very often lonely when

they graduate to independence. Friends are few and hard to find. Relationships with staff are not lasting due to high turnover rates. I receive anxious calls from families asking if we can locate a "friend or roommate" for their high-functioning son or daughter who is currently at home because they are unable to support a community placement alone.

9. S2053 has all the prerequisites of an administrative castastrophe. Every little unit will be a mini institution requiring separate staffs, core teams (professional evaluation programmers and therapists), fiscal and housekeeping personnel, and transportation. Real Estate brokers are busy finding new locations when leases expire and landlords say "move on". This happens with regularity. It will be administratively cost-heavy and impossible to monitor. (See "Costs", page 12)

10. It seems to place some emphasis on foster care and adoptive homes. I would like to stress that as parents we have "loved and lost" because we could not physically and emotionally nurture our handicapped family member 24 hours a day at home. It has been done, but often at the expense of broken marriages and broken family units. This Act assumes that families will stay together. What about elderly parents? What about emotionally unstable family units? What about the single parent?

11. Periodic independent reviews are required in the Act, but are not defined. How frequent is periodic? How comprehensive and independent is the review? In Pennsylvania, parents are not part of the monitoring process. The Pennsylvania 1984-85 Proposed Budget suggests a line item of $400,000 set aside for monitoring this year.

12. Case management services, available to all, will need to be limited to case loads of 12 to 15 persons if they are to be effective. My experience with Pennhurst dispursal shows that case management is just the beginning.

Administrative and supportive staffs from both existing and new provider agencies are required for TIHP, IHP, and IEP meetings, hearings, trial visits, etc. As an advocate in such cases, I can assure you it is not unusual to have to attend a series of planning meetings for one client with 10 to 20 other professionals present each time, some of whom never give input. Meetings may last from 1 hour to most of a day. ALL PARTICIPANTS ARE SALARIED WITH PUBLIC FUNDS, except the client, his family, and the advocate. In some cases, even the advocate (not Pennsylvania League) is salaried. The family is always placed on the defensive and in the minority numerically. This superstructure, one of many, could become a mandate for some 1,000,000 mentally retarded persons according to those who support this proposed legislation. Under S2053, Medicaid funds or an equivalent substitute would be needed not just for one or two years, but a lifetime - 10, 20, or 50 years. Where are the cost studies to support even first year expenditures? Generalization and cost approximations are used as fact. In the section on "Costs", I have developed a financial projection assuming $30,000 per client per year, with and without an inflation factor. (See Costs, page 12) The resulting statistic is staggering!

13. The needs of our people are to be met with Social Security, Supplemental Security Income, Medicaid and Medicare, federal programs in continuing jeopardy because they were never conceived to be more than "supplemental" income. Many states are near bankruptcy. It would appear that our Pennsylvania institutions were upgraded to attract federal dollars that are now convertible through the 2176 Waiver for community resources. The 1984-85 Department of Public Welfare Budget reflects this trend using waivers that have not yet been cleared in Washington.

14. Fiscal audits are a mandate. What about independent program review audits and quality control? In Pennsylvania, Department of Public Welfare (DPW) plans, designs, funds, and monitors its own programs. Pennhurst dispersal originally ordered by the court, also now has the Pennhurst Implementation Team (P.I.T.) who review, approve, and monitor all program plans. THE FOX GUARDS THE HEN HOUSE! When a facility is slated to close, the Director is superseded by a Central Office employee for more direct control. (See Attachment #2, MR Bulletin 99-84-03) February 9, 1984.) Where do we look for due process?

15. S2053 proposes a federal mandate for ongoing Pennhurst type litigation through the federal courts if the terms of the Act are violated. This is probably the most opportune time to discuss how such actions may affect the unsuspecting person. Pennhurst Class members and their families were never forewarned or informed of their official status nor were we as parents allowed to "opt out" our mentally retarded family member. We saw ourselves initially as Defendants - the Plaintiffs claimed to represent our mentally retarded people. They still claim that right. Today, 10 years later, we are at the mercy of the Defendants (Comm. of Pa.) who have determined that they too plan to close Pennhurst Center by 1986 inspite of two U. S. Supreme Court rulings charging that the lower courts "erred." The Pennhurst litigation has been a multimillion dollar income opportunity for all the attorneys involved. With the exception of the legal representatives of the parents, all are paid with tax dollars.

WE TOTALLY OPPOSE SECTION 5 WHICH WOULD ALLOW CONTINUING AND FURTHER OPPORTUNITY FOR PROLONGED CONFRONTATIONS BETWEEN PARENTS AND "ADVOCATES" WHO DO NOT REPRESENT THE INTERESTS OF ALL MENTALLY RETARDED PEOPLE AND THEIR FAMILIES.

I wish to make it clear that Pennsylvania League is not opposed to community living as one alternative in a full spectrum of residential services, but to eliminate the use of the institution by withdrawing funding is not the answer to a growing program. The institution is a natural setting for an experienced resource center, an appropriate evaluation and intake facility, an inpatient and outpatient service for certain kinds of people, and a place where longevity of employment provides experience and knowledge which can be shared. With an open community-institution policy, I am convinced that we could provide far better services to many more people, gain family and community acceptance, and get the best possible return for our financial investment.

Use of public funds should be controlled. A national program of the magnitude provided through the private sector only would be an administrative catastrophe. Just the cost of oversight would outweigh any potential cost benefit. Example: The minute $400,000 set aside for our Pennsylvania monitoring program could be 20 million dollars nationally.

We can provide service to more people in need. We do not object to reasonable Medicaid restructuring. We do see the need for service expansion at a time when funding is not about to be more available

BUT

We do not support the dismantling of an existing system that is the only established resource to serve as backup while we experiment using a population that cannot be expected to respond to our philosophical concepts of what should be. (Attachment #3, Commentary, an experienced professional evaluation of where we are today.) All we need to accomplish our goal is an open mind and a committment to this purpose.

Competition for the available dollars (with opportunity for profit) invites investors not always interested in more than financial return and not always professionally qualified. We need medicaid money to assist congregate facilities that service a severely profoundly multi-handicapped mentally retarded population that is socially the least desirable, most fragile, behaviorally difficult, and very costly to support on a scattered basis. In the community, these severely profoundly retarded people will be the first to be rejected when funding cuts must be implemented.

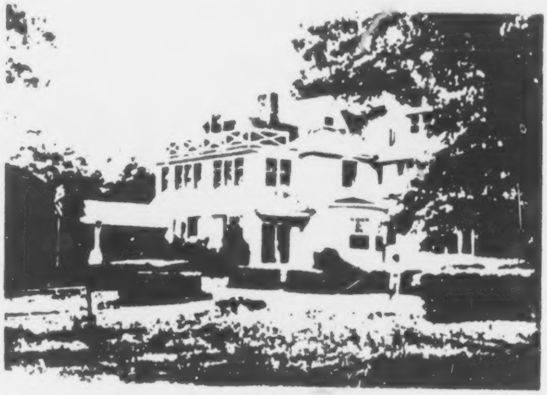
Case Histories of Persons Who Have Been Forcibly Moved

#1. R.A.L., female, age 38, mildly mentally retarded

R.A.L. lived for 18 years in a 28 bed private facility. Her County identified her as a class member, "offered" her a three person semi-independent CLA where she could come and go freely, even to the local bar. She visited the site and emphatically said "NO". As with all clients, she was told, "There is a court order - you have no choice." R.A.L., her family, and advocate continued to object. Rejection of that placement resulted in a recipitous move to a much larger facility (800 beds) where they said she was to be evaluated. She was not allowed her personal possessions, TV, stereo, etc. because she had to share a small room. Telephone privileges were restricted. She increasingly withdrew, did poorly in her work assignment, and constantly asked, "Why can't I go home? What did I do?"

Three months later, she was again precipitously moved into a apartment with a roommate who was not compatible. There was no in-house supervision. She walked 20 minutes in the dark at 6 a.m. every morning to catch the first of 3 bus-trolleys to her workshop. The trip took 2 hours in each direction. She was forced to do food shopping independently even though she was very much embarrassed by her inability to learn the use of money. To and from work she was given tokens. Within three weeks, she ran away, contacted her family, and refused to return to the apartment site. Her County gave her 20 days to change her mind and threatened to cut off her support. Fortunately for R.A.L., the Federal Court has just issued an order extending the jurisdiction of their Hearing Master to cover Class Members being transferred from private facilities. We sought his intervention. He allowed for mediation and a due process that has been denied her previously. It failed. A negotiated settlement between the County and the advocate (without Commonwealth support) allowed for her return to her original facility which she called "home," to avoid what was by now an obvious need for some mental health intervention. The Court agreed.

R.A.L.'s "Home"



R.A.L. is a semi-competent adult capable of some self-determination especially about where she wants to live. At this point in time, she is being given, once again, no alternative, she is being threatened with a return to the apartment site that caused her initial community problem. No consideration is given to her wishes or to the heavier cost factor. (The apartment is at least twice as costly as her "home" facility) R.A.L. could live and work happily at the place she calls "home" and except for a workshop requirement she might live out her life in the beautiful setting where she has friends and could "earn her keep."She is too high functioning for a workshop setting. In a free country, what right do we have to tell people where they should live and with whom just because they happen to be mentally retarded? Welfare recipients receive grants without such restrictions!

#2. P.C., male, age 21, severely retarded, nonverbal, hyperactive

This young man was placed in a large center city Philadelphia apartment 7 months ago. It required a huge lock, a bolt, and a chain lock for security. The area is considered a high crime section, but bordering on a University area. The building, on the corner of a busy intersection, has no recreational facilities and no yard. The closest park is 5 blocks away. The other apartment residents are 60% transient. P.C. has a small single room. His parents reside in another state, no family member lives in Philadelphia. His parents fear for his safety in that setting and wonder about his future. At Pennhurst he had room to run off his excess energy.

P. C. is typical of cases that are increasingly frequent in our experiences as advocates. Behavior problems are being dealt with by using psychotropic medications. Too many of our mentally retarded people are being maintained through drug therapies that are not always adequately controlled. There are no on-site medical professionals in CLAs. In the case of P.C., our first hearing revealed the use of two contra-indicated medications that could have had fatal results. The Hearing Master directed immediate medical intervention and scheduled a second hearing to follow. At that time, the one questionable drug had been replaced by a new member of the same drug family. Nobody was sure of its side effects, but P.C. reportedly was given this to treat Dyskenesia, a palsy sometimes found in mentally retarded people. P. C. had never displayed this problem and showed no symptoms that day. He was still heavily medicated. A behavioral psychologist had charted his February behavior episodes. The young man had had only 4 incidents of about 20 minutes in duration in the 29 day month, but it was felt that medical control was definitely indicated.

A final resolution on this case is yet to come, but as P.C.'s father so aptly put it, "They are making drug addicts out of our mentally retarded kids in the community."

#3. P.H., female, age 37, severely profoundly retarded, microcephalic, epileptic assaultive, hemiplegic, 4' 7" tall

This tiny lady has no habilitative skills, no aptitudes for community living. Her TIHP shows no programmatic goals except "normalization according to the Court Order." She has been in the community for 2 months over her mother's objections. Her Mother, who is P.H.'s only relative is a stroke victim confined to a wheel chair, blind in one eye, partially paralyzed, but spunky. Her goal is to see her daughter safely returned to a more secure institutional setting where she can interact safely at her very limited level with her peers. She lives only to achieve that goal.

P.H. is also being maintained in the community on heavy doses of psychotropic medications which were never given to her at Pennhurst Center. (Attachment # 4 Report of Hearing Master to the Federal District Court) It is well worth the time to review, keeping in mind that it has been prepared by a Court appointed representative with a presumption in favor of the community. I would recommend that you read at the least page 2, para. 1, footnote page 5, page 7 last paragraph, page 10 quotation, footnote page 11, page 13, page 14.

Institutions are perceived by proponents of S2053 as regressive, not least restrictive and a violation of client rights. I feel that P.C. and P.H. are being subjected to abusive treatment, are endangered by the use of dangerous substances in the CLA without close, quality, on-grounds medical supervision.

#4. W.D., female, age 24, cute and lovable, too friendly for her own good, and prone to acting out episodes

She also was placed with no due process over parental objection. W.D. was withdrawn from a lovely family-type private licensed facility and moved into a supervised apartment which was far less desirable, convenient, or socially comparable. Her family retained at different times two attorneys. Both withdrew, one because he discovered a conflict. His firm represented the provider.

W.D.'s family was notified on April 6, 1983 that she was a Pennhurst Class member, therefore, a candidate for the community. On May 5, 1983 she was placed with no prior preparation, no program plan. The Federal Court Order had said our people were to have placements that are "Equal or better." This location is minimal habilitation by comparison, but twice as costly. W.D. is still in that apartment. There have been 2 hearings, multiple meetings, and at this time, the Order of the Hearing Master to retain W.D. at that site has been appealed by her parents with no response in over two months. I understand that some appeals are outstanding for over two years.

#5, J.L., 62 years old, mental age-3 years, 45 years at Pennhurst Center

J.L. knows only Pennhurst. His family is objecting to a proposed transfer to an apartment across the street from the Philadelphia International Airport. He has problems walking, reacts badly to noise, has no awareness of congregate city life, and is proposed to be discharged on a 2176 Waiver - good only to age 65. What happens after age 65? The answer to his brothers's question is a simple, "We'll work on it." Should J. L. have to ge to a workshop at this age? The answer is "yes", everyone does regardless of their age. Recently J.L.'s family received a letter demanding a signed acceptance on the 2176 Waiver form. J. L. will be more confined in the city environment than he has ever been at Pennhurst.

J. L. is only one of many who are being proposed for growth and development in the community after over 40 years in a facility. M. K., age 83, has a son who has spent 42 of his 54 years in Elwyn Institute. We have been able to delay his placement due to M. K.'s recent stroke, but this is not the answer. He is one of five similar cases at that facility. The Pennhurst Class definition includes persons at Pennhurst or in danger of being incarcerated at that facility. 2500 people remain to be placed under this Court Order

#6, P.M., age 15, severely profoundly retarded, physically disabled, needs leg braces to ambulate.

His move was court ordered over parental objections almost two years ago. His family sees no significant change. He is reported to be unaware of his surroundings. His move from Pennhurst cost him the daily services of a licensed physical therapist on grounds at Pennhurst, an outstanding special educational program off grounds, and the devotion of an involved stable staff who literally taught him to walk, respond, and use his braces. He was very special! In the community, he does not have the physical therapy program. Resident advisors (RAs) are trained by the Core Team specialist to administer what it calls physical therapy. Who monitors these programs? Months ago the Third Circuit Court of Appeals ruled that the wishes of this family re P.M. should be respected. There is still no final disposition on P.M.

Gentleman, these case histories are fact! They are but a sampling and they have been summarized. Each has involved months of turmoil and hours upon hours of meetings for the individuals in question and their families. I served as advocate in all but the P. M. case. He has very capable professional parents and we confer. Layers upon layers of paid staff, professional and non-professional, were involved. Had I realized that I might someday be preparing a report, I would have attempted to log data and personnel involved with each case to estimate the expenditure involved in preparation time only before a person even arrives in the community. Is this a valid use of scarce resources? The process is cumbersome. There are no guarantees of success, only that feeling that our people must take risks.

WHY?

COSTS

There is considerable rhetoric about cost of community vs institutional care based on assumptions and often only partial information, but never on true cost accounting studies. In a Congressional Budget Office memorandum, dated December 8, 1983, C. F. suggests that Medicaid savings associated with community placements will increase 10 fold by 1988. Even this report is based on estimates and states that "certified community ICF/MRs (15 beds or less) are assumed to have the supportive services that are required in this provision and, therefore, no increase in cost is expected." Is that realistic? Inflation is an ever present factor. Page 2 of the C.B.O. memo also states that 178,500 people are in institutions. ARC-US estimates S2053 will serve at least 1 million persons or 5 times as many as are currently on the rolls. How can there possibly be savings?

In this section, I will again rely on facts. There is a sampling of audits by the Pennsylvania Office of the Auditor General and the Proposed 1984-85 Budget. Providers will not be identified, but the audit reports would be available on request. They are public documents.

The following three summarized audits will give some insight into community operations:

Provider #1

This facility served 45 persons in 1982 in CLAs at an annual cost of $35,960.93 per client. These rates did not include medical or dental care, specialized professional services, core team, etc. The annual cost for leased vehicles with maintenance was $89,953 or $1998.95/client per year. The annual cost for rent and utilities was $142,874 or $3,174.98/client per year.

Findings and recommendations:

Finding #1 - Provider #1 realized $115,370 in profits from per diem funded CLA program

Finding #2 - Prior years' overpayment of $52,000 should be returned to County

Finding #3 - Provider #1 should return retirement contributions for individuals employed under the Federal Comprehensive Employment and Training Act (CETA)

Provider #2

This is a large proprietary facility serving about 160 persons in the severe profound range. The facility is about 12 years old and reportedly provides a respected quality of care.

This is a two page summary taken directly from the 53 page report which basically listed 15 Findings and Recommendations. There are 8 stockholders.

Finding No. 1 - Income of Approximately $815,608 Is Estimated To Have Been Derived by the Center's Stockholders

We estimate that [redacted] [redacted] [redacted] stockholders, also stockholders in the related corporations, [redacted], Inc., (see Finding No. 3) and [redacted] [redacted] [redacted] ([redacted]) (see Finding No. 2), together received the following in profits and fees for the two-year period ended June 30, 1979.

	For The Fiscal Year Ended June 30, 1979	For The Fiscal Year Ended June 30, 1978	Total
Actual profit and fees paid to [redacted] Rehabilitation Center under DPW contract:			
Profit (see pages 10 and 14)	$111,780	$143,868	$255,648
Directors' fees	14,400	14,400	28,800
Consulting fees paid to a related organization, [redacted] [redacted] [redacted] [redacted] (see Finding No. 2 for discussion)	192,000	192,000	384,000
Estimated income of a related organization, [redacted] [redacted]. (see Finding No. 3 for discussion)	76,460	70,700	147,160
Total profit, fees, and estimated income to stockholders	$394,640	$420,968	$815,608

The total of $815,608 in profits, fees and estimated income directly or indirectly received by the center's stockholders largely resulted from the fees and estimated income generated by the two related corporations (the home and [redacted]). We estimated the fees and income generated by the two related corporations, since the center's management refused to provide financial information or sufficient documentation relating to the two corporations. Except for the contract signed between [redacted] and the center, and the lease signed between the home and the center, the center's management would not or could not supply us with any other documentation to substantiate services being performed by [redacted] or support for the actual costs (depreciation and interest charges on mortgages) incurred by the home.

The $815,608 income and fees received during the two years ended June 30, 1979 represented an average profit to the stockholders based on budgeted costs of 13.2%, which is almost double DPW's intended contracted allowable annual profit rate of 8%. In addition, our calculation of the center's stockholders return on investment for the two fiscal years is approximately 122%. This is equivalent to more than doubling the stockholders investment in just two years. This rate of return received by the stockholders, and permitted by DPW, at the expense of commonwealth taxpayers, is unconscionable. Our calculations are shown in the following chart:

PW should request the return of $503,084 based on the following adjustments or the year ended June 30, 1978:

(1) To reduce health and life insurance benefit expenses, which were incurred on behalf of the stockholders and auditor (see Finding No. 6). ($ 12,765)

(2) To increase employe benefit expenses to reflect unreported union employe expenses. 6,600

(3) To reduce capital improvement expenses for legal fees which were unrelated to the contracted services and compliance with life safety code requirements (see Finding No. 5). (15,768)

(4) To reduce rent expenses for estimated profit taken by [redacted] Inc., which is owned by the same stockholders as the center (see Finding No. 3). (70,700)

(5) To reduce management consulting expenses for unsubstantiated services allegedly provided by [redacted] Associates, which is owned by six of the eight center stockholders (see Finding No. 2). (192,000)

(6) To reduce professional services expenses which were performed by the center's CPA firm (see Finding No. 15). (19,360)

(7) To reduce nonbudgeted directors fees which were paid to the center's eight stockholders (see Finding No. 1) (14,400)

(8) To reduce insurance ($850), repair ($324), and depreciation ($445) expenses related to the nonessential use of an automobile operated by a center stockholder (see Finding No. 9). (1,619)

(9) To reduce miscellaneous expenses unrelated to program operations (see Finding No. 10). (995)

10) To reduce payroll taxes which were inappropriately paid on behalf of the stockholders (see Finding No. 11). (608)

11) To reduce the following expenses to comply with the contractual budgetary restrictions:

Maintenance payroll	($58,967)
Program payroll	(89,654)
Payroll taxes and other benefits	(6,325)
Food costs	(6,899)
Heat and light	(2,619)
Laundry and linen	(7,599)
Kitchen supplies	(1,869)
Office supplies	(422)

Provider #3
This program shows assets of over $1,150,000. It was not possible to determine how many people they serve. The audit reflects the following concerns:

- Some physical sites were considered structurally deficient to house MH and MR clients.
- MH and MR clients are housed together which some county program personnel believe may result in prolonging an MH clients treatment within the program. The prolonged treatment results from the MH persons inability to deal with a low functioning MR person in a daily living environment. Other program personnel believe MH and MR clients living in the same apartment build on each others' strengths. We were informed by county program personnel that [redacted] may be the only residential program in the commonwealth to house MH and MR clients in the same residential setting.
- MH and MR services funds are separate funding sources from the commonwealth. MH expenditures are 90% funded and MR expenditures are 100% funded. When MH and MR clients are housed together the funding source of program expenditures losses its identity.
- There are MR patients within the [redacted] program who do not belong there. As mentioned previously, [redacted]'s program has three different types of residential services which represent stages of progression to an independent setting outside of the MH/MR program. The county administrator's office indicated it believes about half of the MR population of 102 may not belong in a [redacted] type program. They are low functioning MR clients who may not progress into an independent living arrangement.

Findings and Recommendations:

Finding No. 1 - [redacted] Includes Payroll Expenses on Its Financial Statements and Reimbursement Reports for Persons Not Employed at [redacted]. For the Year Ended June 30, 1981 the Expense Claimed for Non [redacted] Employes Was $94,730 and for the Five Years Ended June 30, 1982 Was $388,037 .....

Finding No. 2 - [redacted]'s Financial Statements and County Reimbursement Reports Improperly Included $173,325 of Encumbrances ...

Finding No. 3 - [redacted] Improperly Included $98,759 of Expenses Incurred By Its Building Fund and Related Corporation, Housing Facilities, Inc., in Reimbursement Reports to DPW ......

Finding No. 4 - [redacted] Leases Buildings to HFI and Rents Back MH/MR Counselor Space Which Resulted in Excess Commonwealth Reimbursement Totaling $5,491 ....

Finding No. 5 - [redacted] Did Not Report Offsetting Income Totaling $18,643 to Allegheny County ....

Finding No. 6 - [redacted] Reported and Received Reimbursement for $11,898 of Ineligible Automotive and Auditing Expenses ....

Finding No. 7 - A $73,500 Advance From the County MH/MR Program in 1976-77 Was Not Repaid by [redacted] ....

Finding No. 8 - [redacted] Improperly Classified $5,200 of Fixed Assets Purchases in Fiscal Reports to the Allegheny County MH/MR Program ....

Finding No. 9 - Appraisals for Leased Houses and Apartments Were Not Obtained ....

Finding No. 10 - [redacted]s Contracts for Providing Residential Services Do Not Always Comply with Model Contract Requirements ....

These three reports were intended to point outadministrative and program difficulties that surfaced while auditing costs. All three programs are still operational and under contract for CLA and ICF/MR services

It would be interesting to calculate with more audits to draw from just how much profit will accrue to providers nationally from tax dollars. Program costs will vary from County to County and State to State. We fear that it will not be long before the low income program will feel entitled to a greater financial reward causing escalation of costs.

The following charts were prepared to illustrate the amount of capital needed to provide for lifetime care at an initial cost of $30,000 per year for a client now age 28, assuming 6% and 8% interest rates, with and without inflation. Payments are assumed to be made from both capital and and interest.

INTEREST RATE	INFLATION RATE	ASSUMING CLIENT LIVES TO AGE	CAPITAL NEEDED
6%	0%	70	$484,000
6%	0%	80	$504,000
6%	4%	70	$876,000
6%	4%	80	$999,000
8%	0%	70	$389,000
8%	0%	80	$398,000
8%	6%	70	$881,000
8%	6%	80	$1,007,000

For example, assuming a 6% interest rate and no inflation, it would require a capital investment of $484,000 to provide care to age 70 for a client now age 28. At 6% interest and a 4% inflation rate, this would increase to $876,000. At 8% interest and 6% inflation, it would require capital of $1,007,000. All of the figures assume that the capital would be exhausted at the age shown.

In this statement I have indicated that the Proposed Pennsylvania Mental Retardation Budget for 1984-85 reflects a new direction, expectation of a dramatic increase in federal support for MR community services and less state funding. It is of great concern to parents to see a decreasing State committment by Pennsylvania to our people placing more dependence on others to provide for needs. It was initially a lack of committment that contributed to a decline of the institution more than any other factor. At a time when funds could have been made available for Centers, advocates for the mentally retarded had no endorsement for the provision of a quality life for our institutionalized family members. Only the community as the resource for service was the prevailing emphasis. Meanwhile, Federal financial resources for our institutional population were increased to upgrade physical and environmental care. In Pennsylvania, we did a very acceptable job of accessing ICF/MR certification in a relatively short period of time. Medicaid funding now appears to be one of the very few possible new sources of funds for the community, hence S2053.

The following excerpts will illustrate the new direction:

KEY:	
→	increase
←	decrease
NC	no change

[illegible]

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(Dollar Amounts in Thousands)

Community Services for the Mentally Retarded	1982-83 Actual	1983-84 Available	1984-85 Budget	
State Funds	$ 158,500	$ 169,682	$ 162,320	← 4%
* Federal Funds	7,548	9,423	31,861	→ 228%
TOTAL	$ 166,048	$ 179,105	$ 194,181	→ 8.4%

Provides services mandated by the Mental Health and Mental Retardation Act of 1966 to persons with mental retardation. The Act assures the continuous provision of services to persons in need at the community level.

Federal Funds:				
Maintaining Demonstration Grant	$ 11	$ [illegible]		
Medical Assistance - Community [illegible] MA - Community based		[illegible]	$ [illegible]	→ 400%
Medical Assistance - Community Residential MA - residential		[illegible]	[illegible]	→ 540%
Social Services Block Grant - Community Services in the [illegible] Human Services [illegible] 55	[illegible]	2,400	14,[illegible]	→ 475%
Federal Services Block Grant - Community [illegible]			—	31,861 F.
	$ 166,048	$ 179,105	$ 194,181	→ 6.6%

OBJECTIVE: To enable mentally retarded individuals to live in a community setting by providing services and support to the family and/or mentally retarded individual.

General fund ← 27%
Federal funds → ↑391%
* special funds from lottery 11.5 million

Recommended Program Costs:

(Dollar Amounts in Thousands)

	1982-83	1983-84	1984-85	1985-86	1986-87	1987-88	1988-89
General Fund	$ [illegible]	$ [illegible]	$ 35,720	$ 36,933	$ 38,401	$ 39,974	$ 41,518
Federal Funds	[illegible]		14,500	15,225	15,986	16,765	[illegible]
[illegible]		[illegible]	9,781	15,999	16,410	[illegible]	[illegible]
TOTAL	$ [illegible]	$ 49,126	$ [illegible]	$ 68,157	$ 70,797	$ 73,597	$ [illegible]

Total increase 23%

Program Measures:

		1982-83	1983-84	1984-85	1985-86	1986-87	1987-88	1988-89	
←	Persons added to county MR caseload	6,830	[illegible]	6,766	6,726	6,691	6,662	6,639	
→	Persons removed from county MR caseload	9,788	[illegible]	6,111	6,216	6,296	6,351	[illegible]	
→	Active persons in county MR caseload	[illegible]	[illegible]	35,948	36,563	37,038	37,404	37,684	
←	Persons living in independent and family arrangements	[illegible]	[illegible]	91,431	90,901	90,461	90,111	89,801	
→	Preschool handicapped children receiving early intervention services	6,011	[illegible]	6,101	6,126	6,151	6,176	6,201	*
N.C.	MR persons and/or their families provided family support services	11,548	[illegible]	11,548	11,548	11,548	11,548	11,548	
N.C.	Persons on waiting lists to receive adult day services	[illegible]	[illegible]	1,678	1,678	1,678	1,678	1,678	
N.C.	Persons receiving adult day services	8,823	[illegible]	9,307	9,307	9,307	9,307	9,307	

Community Residential Services

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OBJECTIVE: To enable mentally retarded individuals to live in noninstitutional community settings and to increase their capacity for community and family living by promoting the acquisition of requisite skills and behavior and to provide community living settings.

Recommended Program Costs:

17% increase in state dollars

[illegible] increase in federal dollars

Total [illegible]% increase in federal dollars [illegible]

(Dollar Amounts in Thousands)

	1982-83	1983-84	1984-85	1985-86	1986-87	1987-88	1988-89
General Fund	$ 106,264	$ [illegible]	$ 113,519	$ 118,080	$ 122,782	$ [illegible]	$ [illegible]
Federal Funds	[illegible]	1,192	14,184	22,262	23,158	24,07[illegible]	25,04[illegible]
TOTAL	$ [illegible]	$ 110,436	$ [illegible]	$ 140,322	$ 145,940	$ [illegible]	$ [illegible]

Program Measures:

	1982-83	1983-84	1984-85	1985-86	1986-87	1987-88	1988-89
Persons residing in community residential MR facilities							
At end of fiscal year	5,584	5,968	5,968	5,968	5,968	5,968	5,968
During fiscal year	6,396	[illegible]	6,780	6,780	6,780	6,780	6,780
Additional community residential service capacity							
For those residing in institutions	[illegible]	[illegible]	479	245	201	165	150
For those residing in the community	4	[illegible]	300	275	250	225	200
Residents of community residential MR facilities [illegible]							

31%

Basically, these figures show:

1. 238% → in Federal Funding for County Services mandated by the Pennsylvania MHMR Act of 1966.
2. 400% → in Medical assistance - Community based services
3. 590% → in Medical assistance - Community residential services
4. 95% → Social service - Block Grant
5. * 1000% → Community residential services overall
6. $14,500.000 for early intervention from the Pa. Lottery Fund (designed to be used for Senior Citizens)

It is of great concern that we must look heavily to other resources to fund this program which between 1983-84 and 1988-89 shows no change in the numbers of persons residing in community residential facilities.

Thank you for the opportunity to present our concerns.

STATEMENT OF MARV RAYNES

BACKGROUND: MOTIVATION AND AFFILIATIONS

My wife Annette, and I are the parents of Arnold David Raynes, a 22 year old, neurological impaired severely disabled youth. To review his development from whence he came and what the prognosis was to where he is would require more time and paper than this committee has the patience to endure; therefore let us concern ourselves to today and where he is going. His childhood struggle, although unique to us, is an oft repeated tale told by a parent of a severly handicapped child.

In order to secure rights for our child we recognized that the rights of all handicapped children must be established. This is a fundemental American premise, equality. The system that guides the destinies of our handicapped citizens in my state and other statės does not give on the same magnitude, even or fairly served portions of treatment to all. This imbalance of service delivery is rightly interpreted by parents, families and consumers that by misfortune of a label they have been denied access to treatment thereby being less of a person and certainly a citizen who has lost his constitutional safeguards.

Our concerns for our child and all those handicapped children has forced our involvement and participation in a variety of activities and programs. Some recent commitments include:- JOINT VENTURE-Founder and co-chairman. This newly formed 40,000 state-wide membership parent advocacy group is composed of our children served by the state Mental Health Agency as well as the Mentally Retarded and Developmentally Disabled Agency also including State Education Department and Vocational Rehabilitation, Department of Social Services and those who also remain unserved. On August 5, 1983 we presented our united concerns to our governor at his New York City Office.

PLUS GROUP HOMES, INC.-Advisory Board Member. This is a group of parents of aged out children who tried to establish a community residence for these autistic young adults but had previously met with years of defeat. I am proud that I played a small part in obtaining approval for PLUS so they may develop an intermediate care facility with a New York State share of $100,000.00 of potential capital costs.

RHINEBECK ASSOCIATION OF PARENTS, INC. (RAP)- Founding president and board member. The Rhinebeck Country School in Rhinebeck, New York is a privatly owned residential facility which serves the needs of almost 200 developmentally disabled, mentally retarded and emotionally disturbed youths under age twenty-one licensed by the New York State Educational Department as well as several other states. During 1981-82 we saw thirteen private schools in our state forced, to close their doors forever. New York State makes it virtually impossible for the private for profit sector to operate within its borders. The Rhinebeck School, based on in-state and out of state reviews and audits has been rated as a role model, one of the finest facilities of its type in the state and in the nation, and it to was and still is threatened with extinction. This was a prime purpose in the formation of RAP.

During 1981 services delivered by the Rhinebeck Country School cost less than most similar type voluntary agency facilities and substantially less than the public sector delivering in most instances superior service by comparison was being forced by the state to cease operations. It was the activities of the parents that spearheaded an effort that has to this day prevented this from happening. RAP was the first group to reach out and liason with other similar state and national organizations and became the nucleus in the establishment of a statewide parental effort.
RAP inspired leadership qualities in parents who went on to assume key roles in other groups.. Four RAP members serve on the Lt. Governors Concerned Citizens Task Force on Aging Out, one is a president of a United Cerebal Palsy group, another has become chairman of a major advocacy group plus many have rededicated themselves with new fervor in advocating for the needs of the disabled.
RAP worked to spotlight to government and the public the plight of the "aging out." The first media mention on "aging out" was about RAP parents and the first public forum in New York State on "aging out" was concieved by RAP parents who joined with parents of other schools worked to address this into law.
RAP raised funds to provide extras for handicapped children and continues to see that educational standards for the disabled are not compromised.RAP has prepared testimony before state and federal hearings and has represented parents on an individual basis in securing their rights to various governmental agencies.

ADVISORY BOARD OF THE PRADER-WILLI ASSOCIATION OF NEW YORK STATE - Director of & deeply involved in the affairs of its population. This group, until recently was practically obscure and neglected by government. I have worked with P/W assn. director, hand in glove to secure federal recognition through HHS for this death dealing syndrome. We have received our first state grant. We have worked on representing as a group and individual cases to government the crucial neccessity of programs and proper placements. We are currently working with other groups for the design of the first P/W facility (residential group home) in New York State. We are also targeting on a medical awareness program to make certain that when these problems are found they are correctly diagnosed and treated.

CONCERNED CITIZEN FOR CENTRAL ISLIP- Member of Board which is composed of parents and advocates of patients at Central Islip Psychiatric Center, a state run hospital administrated by the Office of Mental Health . We are concerned with improving conditions of the patients and putting in place an orderly, proper and well planned flow of services when people are moved from the hospital back into the community. We have recently been offered a possible fifty bed site to aide in this transition.

SUFFOLK CHILD DEVELOPMENTAL CENTER PARENT ASSOCIATION-member of it's advocacy committee. Arnold had been a client of this facility from 1969 through 1978 and is currently attending their adult day care program. I have spoken before their parent groups and involved them in the aging out issues. I have testified through state and federal hearings on the urgency of establishing a group home for these young adults. At our town board site selection hearings called to discuss the merits of a community residence brought out forty people to speak against the measure, our efforts turned out 200 local citizens to support the proposed group home. As of this date a first group home (ICF-M/R) is under way and should be ready to accept its new tenants, my son included, this April. A second unit will be ready this fall.

CONCERNED CITIZENS TASK FORCE ON AGING OUT-Member of task force, and played a key role in establishing the initial contact between involved individuals and Lt. Governor Alfred DelBello. I have worked on the goals, objectives,positions and directions that we have taken. I represent the Task Force to the State Education Department and have met with legislative (state) leaders and government officials in preparing state directions in needed extensions of services. We have also prepared media events focusing on the need for services. The task force is currently preparing "Aging Out" day in Albany where parents will meet with their legislators and voice their feelings. This group has also monitored the placement policy of aged out persons in educational/ residential facilities. It is now preparing it's plan to present to government for enactment.

ADVISORY BOARD OF LONG ISLAND RESPITE NETWORK-member of board. The network is a arm of the state Office of Mental Retardation & Developmental Disabilities and serves to prepare respite programs composed of funded residential programs and self-help groups of parents designing respite services. With proper respite machinery in place we can with certainty considerably reduce the flow of individuals into institutionalization.

Among recent activities that I have been involved with included working with the ASSEMBLY OF NEW YORK STATE, SUB-COMMITTEE ON HUMAN RIGHTS , (Chaired by Assemblyman Steven Sanders) in preparation of their recently held hearings on transitional servcies. I also represented parents in presenting to the United States department of HEALTH AND HUMAN SERVICES the plight of the aging out. Prior to my contacting HHS they had ignored this problem. Since their involvement we have seen some movement which includes aging out as a priority for all D.D. councils in their state plan. HHS has through hearings and parent contact presented to the state the fifty most urgent New York cases and has been following up on each. I shall not bore this body any longer but feel enough has been said to establish my concers and credentials.

THE NEED FOR SERVICES

I was made aware of these hearings through the National Governmental Affairs Office monthly ARC's Government Report. In that article they stated, "many have compared the importance and scope of the Community and Family Living Amendments to that of P.L. 94-142, the Education for All Handicapped Children Act. Indeed this legislation provides assurances for mentally retarded and other disabled persons, including those beyond school age, that services necessary to their growth and development will be available within the community, whether in a a family home or a small community facility."

If indeed this proposed legislation could do everything that we understand it to mean, than this bill is of landmark importance. P.L. 94-142 and de-institutionalization have racked severe strains on states and localities as the needs for community programs and residences have sharply grown. An entire new generation of handicapped, brought along the educational ladder to age 21 has come along only for many to find that the next rungs are missing. We, in New York call this "aging out."Oft times parents, feeling abandened by Government, are left to their own devices to secure help for their children. They can not understand why one handicapped child, because he came out of an institution and the state is under court pressure to find a community slot for this person, or this other child is in a foster care system which requires monitoring and treatment receives a priority in placement, or their child may have the misfortune to be diagnosed with a so-called minority syndrome (ie; Prader-Willi, Autistic, Tourette Syndrome, dual diogostic and multiply handicapped to name a few) where little or no programs are available.These generic labels create restrictions that congress must break down. In New York we have about 200 children a year age out of residential schools and several thousand more age out of their local school district program or private sector day-school program in their community that their child had attended. The needs always outpace availability.

Deinstitutionalization is the official state policy however, the practice of "dumping" still continues, although the record states it ended in 1978.Simply stated dumping is discharging of psychiatrically or emotionally disabled persons without support services in place. Patients are thrust out of overcrowded wards or allowed to walk off the grounds. At Manhattan Psychiatric Center in New York City more than 60% of all patient discharges from May through September, 1982 were "escapees." Statewide 8000 patients await placement at a cost of $117.00, per day. Since 1968 due to the new discharge plan, stiffer admission policies, patient deaths and rise in escapees over 70,000 patients have left state hospitals. The plan was to have staff and resources follow the patient back to the community, in reality only the patient left the hospital. In New York State of the 1.9 Billion dollars spent by the Department of Mental Health yearly over two thirds goes to 22,500 patients in it's institutions, the remaining one third funds all other operations including the 125,000 people in communities who need services. Without community support services the result is the most expensive form of care known to western man today, rehospitalization. Many also fall victims to the drug, alchohol situations and find themselves charges of the states criminal justice system. Meanwhile a paradox exist; those who need service can't get in due to stiffer admissions and those who are ready to come out can't, because there is no place to go.

Prior to the Willowbrook Consent Decree there were nineteen (19) state hospitals administered by the department of Mental Health serving a total of 80,000 patients. After the Decree the state designed a new agency, the Office of Mental Retardation and Developmental Disabilities. Today we have a total of fifty one (51) institutions in the state serving a combined population of 33,000 with more employees to administer services and the quality of services delivered in both agencies, in a significant majority of documented cases injures the cases for continuing this costly,ineffective, inhumane warehousing of humanity.

A continuum of services, from inception of diagnosis to that point where services and treatment are no long needed is not only cost effective and probably would represent long range savings to the tax-payers, but would be the humane enlightened approach to a antiquated funded and managed structure.

OBSTACLES

As mentioned earlier when a rung in the ladder is missing development stagnates, in many cases, even regresses. The Intermediate Care Facility, Mentally Retarded or Developmentally Disabled (ICF/MR) is such an example, in New York State. Our state Office of Mental Retardation and Developmental Disabilities (OMRDD) has placed major emphasis on the ICF. Federal guidelines require a heavy concentration of therapeutic services in an ICF. The result has been that a client who may only need one or two of these services is placed in an ICF, (a more expensive alternative) only because one or two of the services needed are not available in a less restrictive, therapeutically intense, and certainly less expensive program.Another problem in the continuum are those clients who have developed to the maximum level the ICF can give but because simpler, less costly programs are not available they must stay in the ICF. Conversly the person who is looking to get in to the ICF is denied access because space is not available. ICF'S have been used in place of needed community residences because they allow the capture of Medicaid revenues. Im many instances local governments have opposed ICFs because of local Medicaid cost sharing. OMRDD responded by allowing full state funding through utilization in those facilities of institutionalized clients, only.

As mentioned earlier we withold treatment to many because of a label. Many disabled in the OMRDD sector could wellbe served by a provider of services in his area but his generic mark becomes a barrier to admission in a program that he could benefit from. It would in many cases be unneccessary to create facilities, and highly costly to serve a minority population when in those cases where their needs can be served by existing services than they should.

Community opposition to group homes is a basic economic issue. The major basis for protection of group homes has been the reinterpretation of the meaning of the word family. Many courts have agreed that a group home which exists as a single housekeeping unit with permanent live in parents that provide a stable and family type environment, actually qualify as a family. While there often is difficulty prior to opening a group home the incidence of hostilities with neighbors after opening are few and far between. In almost all cases group homes have been good neighbors accepted by a once hostile community.

In New York State our site selection law allows the community to oppose a group home at a local town hearing. Communities may offer alternate proposals which take oft-times the form of other properties for sale in other communities. The law allows a 40 day determination by the commissioner after a board rejects a site. Over saturation of facilities is often cited as a objection. There is a strong case to be made that these hearings are a harrasment and a denial of Constitutional Rights as they violate ones freedom of choice soley on minority grounds.

Disabled citizens living in residential programs in New York State represent a broad diversity of functional capabilities. Dollars are wasted and needs largely remain unserved whenever clients are placed in or remain beyond time necessary in a program which does not meet their level of care needs. Such is the case of the ICF and the state run Developmental Centers.

Residential services to those who fall into the Office of Mental Health (OMH) are not only more limited than OMRDD but are characterized by a significant lack of adequate back up services. An example are programs which provide for the development of critically needed community living skills.

It is estimated that 30 to 70 percent of the homeless are product of our mental hygiene system. A briefperiod of hospitalization does not adequately equip many state psychiatric patients for an immediate return to independent living. Experience has clearly demonstrated this reality. What is needed is a viable continuum of supervised living alternatives for those patients. The provisions of these alternatives must be balanced with a gradual diminishing of our reliance on state centers as the primary access point for the chronically mentally ill patient. in need of residential care. This shifting of direction for inpatient care is unquestioned by experienced clinicians treating the chronically mentally ill. Fiscal facts testify to its ultimate economy. A single 30 day stay in a state psychiatric unit cost upward of $4000.00 for a patient under age 62, a months care in a supervised community residence with case management and day treatment could cost the state less than $550.00

RECOMMENDATIONS

WE continue to defend, expand and cover up for our state -run institutional systems. Evidence is overwhelming that the majority being served in those facilities could best be served in a lesser restrictive environment. The system in New York has failed in the hands of OMH and OMRDD. Their can be no room for compromise where the standards of service delivery are in question. The records of our state agencies in these areas is well established and the price tags that taxpayers and consumers has paid has been staggering. If the private sector can offer quality programs at one-third to one-half the cost of the state system, if they can serve more and deliver results for less, why continue with the most expensive least productive system for the care of the disabled in the history of mankind.

A paramount consideration at the planning level should be given to parents of the disabled whose prime concerns include the development of their child to full potential, adequate service and proper treatment to suit individual needs with safe-guards designed to protect their child when they can no longer be present to advocate for their children. As this is a strong humane issue parental input is vital to the success of this program.

It is important that residential programs not be inaugurated without proper programs (ie: workshops, vocational, day treatment) and to assure that needs are properly met a system of case management should be designed using that same person or agency to serve one individual untill need is no longer required.

If this law can bridge from education of the disabled to the adult world than this congress will have the eternal gratitude of millions of Americans.

THANK YOU

Sheila and Joel Small
78 Cedar Ridge Rd.
Newington, Conn. 06111

April 1, 1984

Roderick A. DeArment, Chief Counsel
Senate Committee on Finance
Room 221
Senate Dirkson Office Building
Washington, D. C. 20510

Dear Mr. DeArment:

The following letter represents TESTIMONY OF THE CONNECTICUT COUNCIL ON MENTAL RETARDATION ON S2053-COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983.

We live in the Hartford Connecticut area. We have a Down Syndrome son which is going to be three years of age. Our son has been in the Regional Center program since birth which was June 1, 1981. My husband and I feel that without the help and the need of the Regional Center my son would not of received the help he needed with his early educational program. Studies have shown that the sooner a retarted person is taught, the better he or she would be as a person. The Regional Center also played an important role in our lives such as thesupport, andthe help and the knowledge the teachers have given us with our son.

If the S2053 law is passed, all of the help and support that the Regional Center provides will no longer be in existence. Parents like ourselves needs this facility for support and to help the present and future parents with Handicapped children.

If we didn't have our current Regional Center Program for our son, I don't know how we would of been able to cope as parents without their support and knowledge they have given us. Our son would not be doing what he is doing today if this program was not in existence.

Sincerely,

Joel Small
Sheila Small

Sheila and Joel Small
Parents of a Retarted Child

SFCC, Inc.
SAN FRANCISCO COMMUNITY CARE, INC.

50 El Camino Drive
Corte Madera, CA 94925
(415) 924-6877

February 28, 1984

Roderick A. DeArment, Chief
Senate Committee on Finance SD-219
Dirksen Office Building
Washington, D.C. 20510

Dear Chief Counsel DeArment:

I would like to take this opportunity to thank you for responding to my letter. I am sorry that I was not able to testify in person for the committee, but would like to use this letter as a form of written testimony to be presented to the Committee on Finance.

I am a disabled person, who lived in a state hospital for years. I now live in a community program where I feel my life is generally better. I do not want to live in another state hospital and would refuse to go if ever the situation arose.

I would like to go on record stating my full support for Senate Bill S2053. I feel the government should spend Medicaid monies on community programs and stop the support to state hospitals.

Sincerely,

TUNNEL WILLIAMS

STATEMENT Marilyn Straw

RE: "Community and Family Living Amendments of 1983" (S2053)

I have a 23 year old son who has been living at our State residential facility for the Mentally Retarded (approx. 550 residents) for the past 10 years - before and after they received Title XIX dollars. Needless to say, there have been vast improvements.

I have also been a volunteer there for the past 10 years (1 day per week) working directly with various residents on a 1-1 basis. I am a parent representative on the institutions Human Rights Committee and a Board member of the Home Association (sort of a PTA).

Because of these varied experiences I feel that I am able to address this bill (S2053) with more knowledge than the average parent, about the workings of an institution of this size.

Not all institutions are "bad" if done right! Those that have become Intermediate Care Facilities for the Mentally Retarded funded by Title XIX have accomplished this. By having to comply with Federal regulations, the states allocated enough money to provide proper staff ratio; enough money for daytime programs, directors, and support personnel; enough money for upkeep and maintainance and have reduced the number of residents to a manageable level, usually between 400-600 people.

Our State facility (Woodward) offers an excellent environment for the multiple handicapped or severely retarded individual with fragile health because of it being a "medical model". If these same people lived in the community they would have to be transported by para-transit buses from group homes to workshops or "centers" and then back again to group homes at the end of the day - in all kinds of inclement weather and I question their comfort and health. This would need to be done in order to provide them with a variety of experiences away from their living environment. At Woodward this is accomplished by interconnecting passageways from one building to another and it works beautifully.

Woodward also offers a protective environment for the physically active person not capable of handling the same freedoms in a community setting because of traffic, becoming lost, or being molested and yet still gives them a sense of independence and worth. It also offers those retarded individuals with adverse social behaviors a place to be re-trained or "contained", whatever the case may have to be. Any adverse behavior that is displayed in a community unfortunately "labels" all retarded people as being the same.

I have also actively served on the Board of Directors of ARC/Polk Co., Iowa for the past 8 years and have been a faithful supporter of community based facilities. Our ARC successfully operates six Group Homes in Des Moines, Iowa for moderately retarded adults and provides a daytime workshop for approx. 250 people.

So, even though I wholeheartedly support the philosophy of community facilities for the mentally retarded, I also am convinced that we need a wide range of services to be offered so that all levels of functional ability are addressed. Those "institutions" that are being run properly with Title XIX funds need not be closed down but rather "grandfathered" in, as they do fill the needs of a definite portion of the mentally retarded population.

Marilyn Straw

929 - 39th St.
West Des Moines, Iowa
50265

Senator John H. Chafee
Dirksen Building, Room 567
Washington, D.C. 20510

Dear Senator Chafee,

We are writing to inform you of our opposition to "The Community and Family Living Amendment of 1983", Senate Bill #2053, in its present form. We are definitely in favor of the concept of the bill and greatly appreciate your taking the initiative to improve conditions for the severely disabled individuals of our nation. We most strongly disagree with the idea that this can only be done in small (10 bed, widely dispersed) community facilities.

There should indeed be an effort made to close any size facility (state or private) which does not meet standards of high quality. Many of the standards which are contained in the bill (such as trained staff, interdisciplinary team formation of individual plans of assistance, and adequate monitoring of facilities) are excellent. The assumptions:

1. that these services can only be best rendered in 10 bed facilities which are not in clusters but widely dispersed,
2. that the resulting increased numbers of such facilities will be able to be adequately supervised and monitored, and
3. that the larger number of smaller facilities will be more economically feasible

are not realistic.

There are currently facilities of 35 - 200 which do a good job in providing for DD individuals. Our severely retarded daughter has had the privilege of residing in two of them. They meet existing quality standards and strive to give the individual, personal dignity and acceptance in the community at large as well as providing good medical, behavioral and educational services.

We believe that existing facilities which can meet the standards you are striving to set (regardless of their size) should continue to be supported legislatively and monetarily (Medicaid funding). We also recommend that as poor quality facilities (state and private) are phased out, sufficient community facilities (varying sizes) be provided to meet the needs of all DD individuals who require such services. We have every confidence that this bill can be revised to provide the direction and incentives necessary.

Thank you for your attention to our concerns.

Sincerely,

Mr & Mrs William J. Sigle

Mr. and Mrs. William J. Sigle
2011 McDaniel Avenue
Evanston, Illinois 60201

copies: Senator Robert Dale
Senator David Durenburger
President Ronald Reagan

February 27, 1984

Community and Family Living

Amendment of 1983, S. 2053

I am Ruth Snyder, the parent of a mentally retarded daughter. I live at 8301 Franwood, Austin, Texas 78758, telephone 512 + 453-7145.

I have been an active volunteer in the field of mental retardation since 1955. Together, my husband and I founded the Parent Association for the Retarded of Texas (PART). PART is an association of parents, guardians and other close relatives of mentally retarded persons living in state operated facilities for the mentally retarded in Texas. This organization will have its tenth anniversary in June and has 3,500 plus members.

My husband and I jointly received the Texas Department of Mental Health and Mental Retardation Commissioner's Award in 1979 for having an impact on the greatest number of mentally retarded persons in the State on a volunteer basis.

I represent this group of people who are vitally interested in their mentally retarded children. They want me to express to you our strong objection to S. 2053. We know that you want what is best for the mentally retarded, so we ask that you please hear our point of view.

I want to thank each of you for your interest and concern for the handicapped population of the nation. I will address specifically the needs of the mentally retarded, as this is the handicap of which I have first hand knowledge.

Mental retardation is a condition that appears during the developmental years and remains throughout one's life time. If you took all of the mentally retarded people in the world and charted a curve, it probably would fit neatly over the curve for the so called normal population. If the total population were retarded, then the mildly retarded would be the Einsteins of the population. At the other end of the curve you would find those who are totally dependent on others for their very existence.

In Texas the State Schools (institutions) provide good and loving care for the mentally retarded who are residents. S.2053 would eliminate the state schools as an option for the mentally retarded by cutting off federal funding.

Residents of the Texas State Schools are not isolated. The Community comes on campus in large numbers as volunteers. Some of these volunteers work with clients on a one to one basis while others come in groups. Many in both catagories volunteer on a regular basis.

Residents of Austin State School have been to the Govenors Mansion for a party, to the Sheraton-Crest Hotel for dinner, in both large and small groups, to Spaghetti Warehouse (a good analogy perhaps- it is a fine Italian Resturant) as well as most of the quick food places in the area. Their love for fast foods - may indicate their mental age - I recall a friend taking his two young grandsons on vacation and making the mistake of telling them they could choose where they wanted to eat. He ate McDonald hamburgers for a week.

Residents of all the Texas State Schools have access to the Leander Rehabilation Center where they can go for a day or a week. On this 756 acre ranch there is fishing, horseback riding, swimming, picnicing, hayrides, with a varity animals available for petting by clients. Accomodations range from primative cabins to those with heating and airconditioning.

Austin State Schools residents have been to most of the concerts, country western shows, ice capades, circuses or whatever entertainment that has come to Austin. They go to the San Antonio Zoo, Six Flags over Texas in Arlington, Astro-World in Houston, State Fair in Dallas, and to the beach on the coast of Texas. Some residents participate in the choir festival each year which takes them to cities throughout the state. Some of the residents are involved in Special Olympics and go to the local, regional and state meets. Those who win go on to national competitions.

Other schools provide similar activities for their residents. Some have made trips to Mexico, Grand Canyon, and to Disney Land in California.

The "Music Makers" at Travis State School have been invited to the National Arts festival at the Kennedy Center in Washington, D. C. in May, 1984. They plan to go.

We have many fine employees working in State Schools (institutions) in Texas. During the last session of the Texas Legislature a law was passed which provides for additional screening of applicants before they are hired by the Texas Department of Mental Health and Mental Retardation. We have in place rules which allow for dismissal and prosecution of staff who abuse clients or who fail to report abuse when they have knowledge that abuse has occurred.

Incidents of abuse in Texas may seem high for records are kept on abuse for verbal statements which tend to demean a client, to overreaction by an employee who is trying to protect themselves from a client who is very upset and acting out, as well as, those who intentionally abuse clients.

We have a number of employees who are also volunteers. They provide many extras for clients. Some take them home with them on a regular basis others provide extras on special occasions.

An excellent example of employees who care was recently demonstrated when a client from Austin State School had to go to Houston's M.D. Anderson Hospital for very complicated cancer surgery. Some of the staff on the unit took up a collection so the family could be with their loved one for a longer period during this traumatic time. The staff who went to Houston to help with the client did so on a volunteer basis with no extra pay. Staff from a sister school volunteered to stay on the night shift after working their regular day shift without any extra pay or time off. I am sure there are other examples of staffs personal sacrifice throughout the state that would be equally as dramatic.

Each day more mentally retarded persons are being born, and, as a result of medical progress, more people with severely handicapping conditions, both mental and physical, are living longer. It certainly will not be cost effective to provide small individual settings with the constant nursing and medical care they will need.

The community care waiver, which most states have already applied for, provides federal funding for those who can benefit by living in a small home but allows funding to continue for those who benefit more from the protected campuses of the state schools (institutions). Why would anyone want to take away a good option from a group of people who are happy whith what they have? More and more mentally retarded persons are becomming mentally ill because of the pressures put on them to perform in areas in which they are incapable of performing. Small changes such as moving their beds from one place in the room to another can take weeks of adjustment for some mentally retarded persons.

There are no definitive studies of the relationship between costs and facility size. Certainly the Congressional Budget Office report to Christine Ferguson, dated December 8, 1983, is based on assumptions and false premises.

Cold hard facts and figures are very elusive, but you can rely on common sense to tell you if you provide services for many people in many settings, it will cost more than if the service is provided in one location where cost can be shared.

A good analogy would be a large family living in a large house together. A family of eight could live in a home that has been paid for with the only remaining expenses being, taxes, insurance, and utilities. In Austin, Texas, a four bedroom home in a middle class neighborhood, taxes are approximately $1500 per year, insurance for a brick construction near a fire station is approximately $650 per year, a and all utilities could be as low as $250 per month, or between $600-$800 maximum.

By using the lower figures for expenses, the family of eight could live in their home for $5750 per year.

If one family member moved into an apartment costing $325 per month and only had to pay his electric bill, he possibly could keep his bill as low as $35 per month for electricity, a very conservative estimate.

If two of the family members moved into a two bedroom house and paid $450 per month, they possibly could maintain utility bills averaging $100 per month.

If three of the family members moved into a three bedroom house paying $500 per month, the utility bills would be at least $150 per month. This means that it would cost the children $18,720 per year to have a place to live, while the parents would continue to pay the same expenses as they did before the children left. Now the family pays $24,470 per year to have a place to live, compared to the original $5750.

The figures I have given you are very conservative for a middle class neighborhood in Austin, Texas. These figures do not include many other necessities of life such as food, clothing, medical and dental expenses, and transportation.

In a regular household a telephone could conceivably be considered a luxury, but for the severely handicapped, it could mean the difference between life and death.

I know from personal experience, as well as from the experiences of other members of PART, that our children will be much more isolated in a small house in the community than they are at a state school (institution) in Texas where they can move about the campus area freely to attend classes, to go to workshop, to visit the doctor and dentist, to use the barbershop or beauty shop, to enjoy the recreation areas, to swim in the enclosed year-round swimming pool, to worship in the chapel, and to take advantage of all the other services offered to them.

People from the normal population are currently moving into secure neighborhoods with locked gates and security guards patrolling the area, or into apartments where no one enters the building without first identifying themselves. Yet we, who are parents of mentally retarded children, are being asked to place our loved ones who are the most vulnerable to exploitation, out in the "community" to take the risks the normal population is no longer willing to take.

The State Schools (institutions) as we know them in Texas are the least restrictive, most cost effective, appropriate place for our children. We chose this service. We want other parents to be able to choose the service which is best for their retarded children and the family as a whole. The current funding mechanism allows for this.

ARC-US has promoted S. 2053 as being the will or desire of their general membership and has stated that millions of dollars will be saved. At ARC-US national meeting in Detroit a number of people in attendance told me that they had never heard of the proposed bill until a short time before going to Detroit --the times varied from two weeks to two to three months--and they were very much opposed to the bill.

The Lufkin Council, which is affiliated with ARC-Texas and ARC-US states that they were never given an opportunity to vote on a resolution which recommends closing the State Schools. The comments at their meeting on February 2, 1984 were almost unanimous against the resolution to close State Schools.

The Dallas ARC reported in their newsletter that they had voted not to support S. 2053 and I have been told that other ARC groups have done the same thing.

I dare say that many individual members share the same views as PART members and would agree with the fall issue of Texas Talk, the newsletter of ARC-Texas, which states: "We must recognize that on an individual basis, cost may be higher than those in an institution."

We do not need federal laws which allows federal funding for only one type of service. This would be discrimination in its worst form.

Statement from SPARS (Parents and Relatives of Gulf Coast Center residents located in Fort Myers, Florida)

Gulf Coast Center is a very nice residential center, located on 600 acres in east Lee County, Florida. Our children live in small cottages which have been renovated to provide a more home-like environment. Our children have access to parks. playgrounds, swimming pools, gyms, training schools, complete medical services, vocational and horti-therapy programs, and all kinds of special therapies; all located on the Center's landscaped grounds. The Center has a Staff Development Department to provide ongoing staff training to better serve our children. In addition, Gulf Coast Center has a full time Quality Assurance Department which continuously monitors the quality of care and treatment our children receive. Our children live in a place that is designed for them and respects their right to dignity despite their handicaps.

Most of the residents of our Center are profoundly retarded, needing very close supervision and care.

Under the ICF/MR medical program our Center has made many improvements in the care and treatment of our children. We feel that the enactment of the Chafee Bill would destroy all the progress that we have made.

We would like to make the following points:

1) The cost of care at Gulf Coast Center is currently $31,000 per year per client. This compares to approximately $34,000 for the private community-based ICF/MR's. Currently the private community ICF/MR's serve only primarily moderately retarded clients. They would require more money to serve people who have multiple handicaps as well as being profoundly retarded. Also, the cost of care for small 6 to 8 bed ICF/MR facilities for people with severe handicaps or behavior problems would be much more expensive than the current community ICF/MR rate due to the fact that the cost of services would be spread over fewer clients, thereby raising the cost of care per client.
2) We feel that monitoring and support services would need to be drastically increased in order to assure a satisfactory level of care in the small facilities. Such activities would be much more difficult and who would be accountable for the care of our children? Currently, we know who to go to to get action when we have concerns or need help.
3) Zoning in Florida often prohibits the building of care facilities in nice neighborhoods. Will our children be forced to live in less desirable neighborhoods or business areas? Is this normalization or mainstreaming?

4) Several parents in our group have had bad experiences with "community" facilities and are pleased with having their children living in Gulf Coast Center.
5) We are the parents of the people that this Bill would affect. We feel that our concerns and input should be heard. We feel that the Chafee Bill is much too drastic in its scope and impact, and will end up costing the taxpayer more money! We are taxpayers too!

Will our children's interest be best served by this extreme Bill? We don't think so. We as a parents' group of retarded persons, support the placement of retarded persons in Community settings whenever practical. We do not feel that the principle of a client's right to live in the Community should be confused with a mandate to move clients to the Community as we feel this Bill proposes.

Thank you for the opportunity to voice our concerns.

Julie Fous
Julie Fous
President, SPARS

February 20, 1984

address: 8949 Beacon Street
Fort Myers, Fl. 33907

Oak Lawn, Il.
Feb. 7, 1984

Mr. Roderick DeArment,
Chief Counsel and Staff Director
Committee on Finance
U. S. Senate, Room SD219
Washington, D. C. 20510

Dear Mr. DeArment:

Please include the attached letter as testimony for the written record.

Yours very truly,

Anna Timm
9128 S. Pulaski Rd.
Oak Lawn, Il. 60453

I request that Senate Bill #S-2053 be voided in that it does not meet the requirements of the severely handicapped residents in institutions at this time.

There are different categories of retardation and it is not practical, humane nor economical to phase out all institutions within a 10-year period and place the severely retarded into community homes housing no more than 10 people. If homes would have to be purchased or built for every 10-people group could you realize the number of homes that would have to be built and then, too, what would happen to the institutions that are now housing these people.

Some of these patients have been in institutions for 20 to 40 or 50 years, are non-verbal, cannot take care of themselves, need medication, etc. Could you place yourself in this position?

We have money for the space program, defense, and help all other people in the world, but we have no heart for our own retarded handicapped citizens.

United Cerebral Palsy Associations, Inc.
Governmental Activities Office
Chester Arthur Building, Suite 141
425 I Street N.W.
Washington, D.C. 20001

(202) 842-1266

STATEMENT

RESPECTFULLY SUBMITTED TO THE

SENATE COMMITTEE ON FINANCE

SUBCOMMITTEE ON HEALTH

ON

S. 2053, THE "COMMUNITY AND FAMILY
LIVING AMENDMENTS ACT OF 1983."

ON BEHALF OF

UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

Prepared by Dr. E. Clarke Ross, Director

UCPA Governmental Activities Office

March 9, 1984

LEONARD H. GOLDENSON
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EARL H. CUNERD
EXECUTIVE DIRECTOR

UCPA respectfully submits its tentative position on S. 2053, the "Community and Family Living Amendments Act of 1983." The tentative position has been developed in joint session by two committees of the UCPA Board of Directors-governmental activities and professional services program. The UCPA Members of the Corporation will consider this tentative position at its May 1984 annual meeting.

UCPA TENTATIVE POSITION ON S. 2053

(1) UCPA reaffirms three programmatic assumptions which endorse the concept behind S. 2053:

(a) Most of the current institutionalized population can have their needs met in the community.

(b) Even severely disabled persons have the potential for growth and development.

(c) Persons with disabilities benefit from regular and substantial social contact with nondisabled peers.

(2) UCPA operates on the assumption that S. 2053 covers only Medicaid certified long term care facilities (which are skilled nursing facilities, intermediate care facilities, and intermediate care facilities for the mentally retarded).

(3) UCPA endorses the partial phasing-out of institutions.

(4) UCPA rejects the S. 2053 proposed facility size threshold of three times the average household.

(5) UCPA endorses the application of the least restrictive environment concept to a cascade of service placements with a ceiling on all residences of 50 beds. UCPA supports the phasing-out of all Medicaid certified long term care facilities over the size of 50 beds. The 50 bed threshold is established in recognition of the inappropriateness of 15 (small ICFs/MR and grandfathered in by S. 2053) because of special population considerations. Facilities should include no more than 15 residents with three exceptions: the medically fragile where no other appropriate facility is available, rural areas, and large densely populated urban areas with limited housing stock where such facilities are appropriate to its community. But, in no case would the number of residents exceed 50.

(6) UCPA recommends that the federal SSI definition of disability be used in targeting eligibility for S. 2053.

(7) Existing UCPA corporate policies and positions also relate to S. 2053. These include the least restrictive environment, individual choice, individual plans, funding following the individual, the need for a secure and stable community services federal financing source, endorsement of alternatives to institutional care and incentives for deinstitutionalization including higher matching rates for community services and lower rates for institutional services, endorsement of a

federal government responsibility for promoting national leadership in developing appropriate services to persons with disabilities, and quality assurance approaches including accrediation.

APPLYING THE LEAST RESTRICTIVE ENVIRONMENT TO THE "CASCADE" OR "SPECTRUM" OF SERVICES

UCPA of Pittsburgh and its member Dr. June Mullins attempted to conceptualize the application of the least restrictive environment (LRE) to living arrangements as used in implementing P.L. 94-142, the "Education for All Handicapped Children Act." Dr. Mullins also relies on Evelyn Deno's model as described in Exceptional Children, 1970. Dr. Mullins and her Pittsburgh associates believe the LRE model is appropriate for adult living arrangements. The approach is based on an assessment of the individual's needs and appropriateness of the residential placement.

P.L. 94-142 requires "that to the maximum extent appropriate, handicapped children, including children in public on private institutions or other care facilities are educated with children who are not handicapped and that special classes, separate schooling or other removal of handicapped children from the regular educational environment occurs only when the nature or severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily." The placement is to be determined at least annually; is based on the individualized education program which is developed by an interdisciplinary team, the child, and the child's family; and "is as close as possible to the child's home." The P.L. 94-142 regulations state that "in selecting the least restrictive environment, consideration is given to any potential harmful effect on the child on the quality of services which he or she needs."

The P.L. 94-142 regulations contain a section on the "Continuum of Alternative Placements." This section specifies that "(a) Each public agency shall insure that a continuum of alternative placements is available to meet the needs of handicapped children for special education and related services. (b) The continuum required under paragraph (a) of this section must: (1) Include the alternative placements listed in the definition of special education under 121a.13 of Subpart A (instruction in regular classes, special classes, special schools, home instruction, and instruction in hospitals and institutions). and (2) Make provision for supplementary services (such as resource room or itinerant instruction) to be provided in conjunction with regular class placement."

Dr. Mullins has developed the following "Spectrum of Living Arrangements for Developmentally Disabled Adults:"

Move up as fast as possible toward less restrictive environment

Move down only when absolutely necessary toward more restrictive environment

Independent living in apartments/houses with related services as needed, including attendent care.

Supervised independent living in apartment/houses with related services as needed including attendent care.

Family like group home integrated into the community activities with related services.

Residential institutions with community activites available to residents.

Residence with parents or foster parents with related services including respite care.

Residential institution providing total care accessible to family friends and other community members.

Residential institution providing total care in area distant from residents community or origin.

Hospital setting needed for necessary medical services.

UCPA endorses the application of the least restrictive environment to a cascade of service placements with a ceiling on all residences of 50 beds. The state would be obligated, in developing the individual plan, to clearly document why the individual could not possibly live in the least restrictive setting. Having documented that decision to the satisfaction of the individual, family, and interdisciplinary team, the process is repeated for the next least restrictive setting. The process is continually repeated until the most appropriate setting in the LRE is located and agreed upon. UCPA believes that this proposal is the most meaningful of our suggestions to the current debate on S. 2053.

SPECIAL CONSIDERATIONS FOR THE MEDICALLY FRAGILE

An issue constantly raised as a concern related to S. 2053 is the level and appropriateness of services for the "medically fragile" person with a developmental disability. Mary Smith, in her February 1984 Congressional Research Service background paper, estimates that "25 to 30% of the institutionalized MR/DD population is either medically fragile or has very severe behavior problems." She does not provide an operational definition of "medically fragile" but characterizes them as "MR/DD persons who require 24-hour nursing care and frequent physician services."

John Siepp, Director of UCPA's Professional Services Program Department, observes that there are a variety of definitions and concepts within the UCPA professional services community regarding the term "medically fragile." Some of these views are based on a more clinical definition of what constitutes "medically fragile" conditions. Other views are based on the manner that current Medicaid ICF/MR rules force providers to define the term to ensure reimbursement.

Patricia McNelly, R.N., Chairman, UCPA Professional Services Program Committee, has offered the following tentative working definition. "Medically fragile persons are those persons who experience an instability of their health condition which require close, intensive, and daily professional nursing supervision." These persons would require at least weekly physician visits. Examples of medically fragile conditions would include serious metabolic disorders, very high risk for aspiration, and unusual and complex position and handling to sustain life.

Two Senate Subcommittee testimonies addressed the particular situation of the medically fragile. Karen Green - McGowan, R.N. and Sister Barbara Eirich. We reinforce their statements.

O'Keefe Ashenden Lyons & Ward
A Partnership Including Professional Corporations
One First National Plaza - Suite 5100
Chicago, Illinois 60603
(312) 621-0400

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John F. Ward, Jr., P.C.
Richard J. Ciecka, P.C.
Kevin M. O'Keefe
Dennis M. O'Keefe
J. Michael Heaton
Daniel W. Coyne, P.C.
Patrick L. Moore
Michael W. Ward
John R. Ashenden
Cynthia J. Flaa
Elizabeth L. Oracle

Robert G. Hanson
John F. Dobler
Of Counsel

February 14, 1984

Senator Robert Dole
Finance Committee Chairman
U.S. Senate
Washington, D.C. 20510

DATE: February 27, 1984
SUBJECT: Community and Family Living
Amendments of 1983, S, 2053

Dear Senator Dole:

My fourteen year old daughter, Kristen, is currently a resident of St. Mary of Providence School, 4200 North Austin, Chicago, Illinois. St. Mary of Providence School is a school and home for the mentally retarded. It is run by the Sisters of St. Mary of Providence, a religious order dedicated to the care of the mentally retarded. Kristy attended the school for several years as a day student. In September of 1983 she became a full time resident. The transition has proved to be a wonderful success. For the first time in her life, Kristy is part of a community in which she has peers. She loves living at "the apartment", as she calls it, and yet she comes home to visit every other weekend and for all holiday vacations. It's a wonderfully balanced solution to Kristy's problem. She now has the specialized environment needed for her growth and development and we still have Kristy as a regular part of our family.

It has come to my attention that the Community and Family Living Amendments of 1983 would propose to eliminate all institutions for the mentally retarded containing more than 10 mentally retarded persons. I understand that the word "institution" often carries with it a negative connotation, especially when talking about the mentally retarded. Such a simplistic approach, however, ignores the facts that many of these institutions are the answer to many a retarded child's parents' prayers. Prayers not only for health and assistance in sharing the parents' burden in caring for their child, but the answer to finding an environment for our retarded children where they can make friends and learn to help people even less fortunate than themselves and develop a sense of self-worth and pride.

Kristy loves St. Mary's and my wife and I know the dedicated women of the Sisters of St. Mary's of Providence treat her with loving care. Let's fact it, the good Sisters aren't doing it for the money. Care of the mentally retarded is their calling in life and anyone who spends any time around them will see that they genuinely love their work. If they didn't, they wouldn't stay. I can't tell you what a great comfort this is for parents to know that their retarded child is in the hands of such dedicated, loving people. The good Sisters love is evident everywhere, in the spic-n-span physical plant in which they live and care for their charges to the wonderful enthusiasm of the helpers, teachers and social workers who assist them in the care of Kristy and her friends. Anyone who conjures up the image of an "institution" as a cold, dark, friendless place need only visit St. Mary of Providence to forever change his attitude about "institutions" per se.

Some day Kristy may be ready for a group community home. Accordingly, I am not interested in doing anything to discourage the funding and development of group community homes. But group community homes are not the sole answer. An institution such as St. Mary of Providence by virtue of its larger size is able to provide many additional services and facilities for the children. Economics alone would prohibit group community homes from providing these same services.

I feel we need both the group community homes and the larger institutions so that parents will have a choice as to what best suits the needs of their mentally retarded child. Support group community homes, yes. But close down institutions that are already meeting the needs of our retarded children, No! Such a move is senseless, unnecessary, and potentially disasterous. Institutions such as St. Mary's should be encouraged, not discouraged.
Kristy is happy there, we are happy there and the good nuns and the wonderful people that work with Kristy know the joy that a retarded child can bring to them while they work at St. Mary's.

Don't tamper with success! I beseech you not to take Kristy's "apartment" away from her. I urge you to vote "No" on the Community and Family Living Amendments of 1983. The objective of the bill may be laudatory but the exclusiveness of the remedy reeks of a philosophical intolerance and insensitivity to the needs of Kristy, her friends, their parents and the wonderful dedicated people who have given so much of their lives to the care of retarded in institutions such as St. Mary's. Don't destroy the St. Mary's of this country, for you will risk destroying the Kristys and their parents too. Vote "No" at all costs.

Very truly yours,

John F. Ward, Jr.

JFW:jts

WOODHAVEN
CENTER FOR SERVICES TO PEOPLE
2900 Southampton Road/Philadelphia, Pennsylvania 19154
Woodhaven Center Board of Trustees

TESTIMONY

On Behalf of Passage of
"Community and Family Living Amendments Act 1983"
S. 2053

as offered to the
United States Senate Committee on Finance

March 16, 1984

by

Elizabeth B. Green, President
Board of Trustees
Woodhaven Center

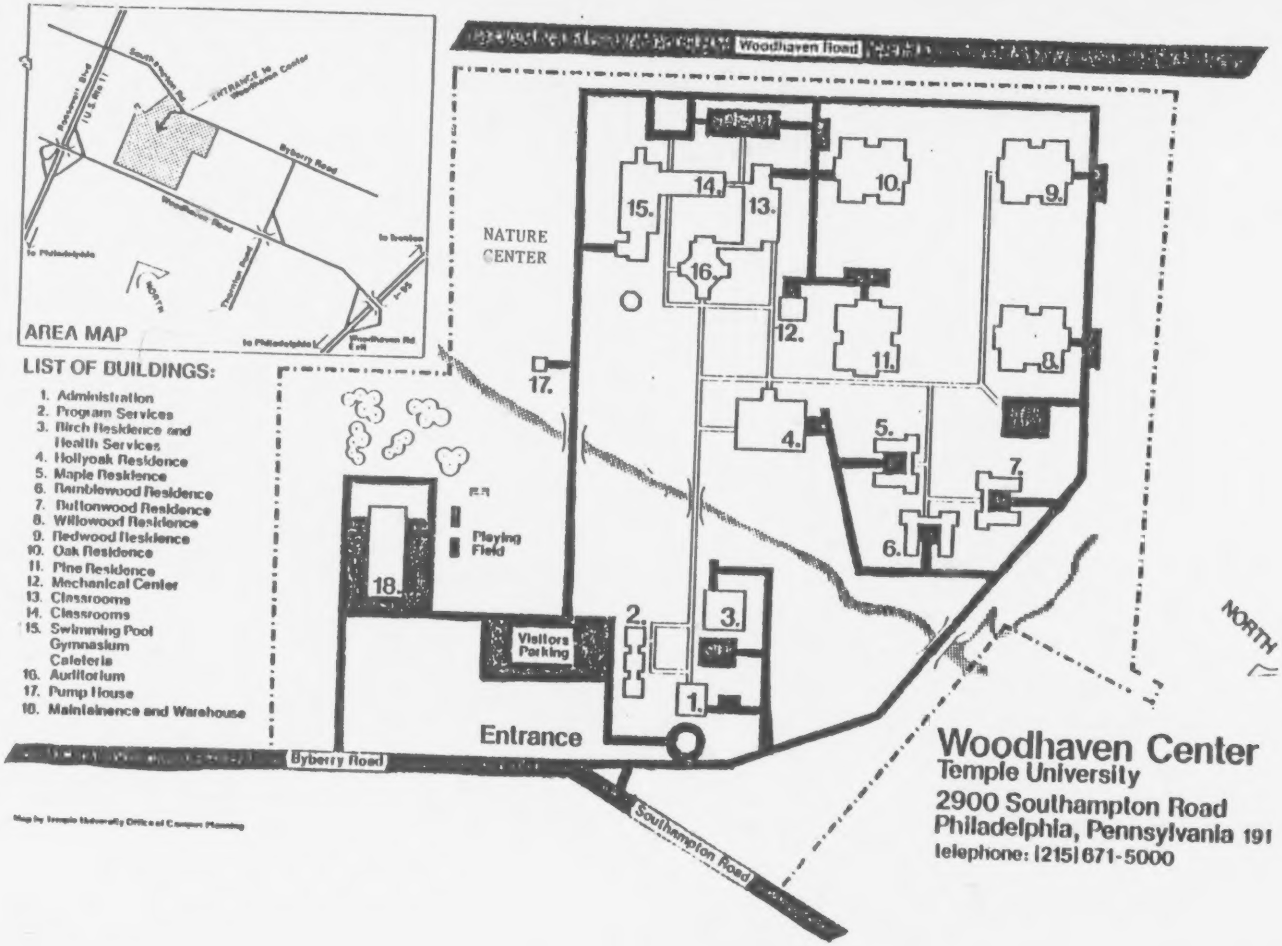
Lila Cohen
Kenneth A. Fegley, Ph.D.
Leona Fialkowski
Bernard Glassman, Esquire
Miriam L. Golub
Helen Herrick, Ed.D.
The Honorable William Mazzola
Crata M. Vaughn, Ed.D.

Operated and funded under a contract between Temple University and the Pennsylvania Department of Public Welfare

On behalf of the Board of Trustees of Woodhaven Center (Philadelphia, Pennsylvania), I would like to go on record as advocating the concept of federal aid to support living arrangements as found in S. 2053, "Community and Family Living Arrangements Act of 1983".

The program at Woodhaven Center is provided by Temple University under a contract with The Department of Public Welfare of the Commonwealth of Pennsylvania. It is a nationally known residential program providing short-term intensive, habilitative training presently unavailable to individuals in their home communities.

The Woodhaven Program serves 380 people at our main campus and the Extension Program at Philadelphia State Hospital. In addition to direct service delivery, the program is involved in evaluation, research, training, and public education. It is one of the largest university affiliated programs of its kind in the United States.



LIST OF BUILDINGS:

1. Administration
2. Program Services
3. Birch Residence and Health Services
4. Hollyoak Residence
5. Maple Residence
6. Ramblewood Residence
7. Buttonwood Residence
8. Willowood Residence
9. Redwood Residence
10. Oak Residence
11. Pine Residence
12. Mechanical Center
13. Classrooms
14. Classrooms
15. Swimming Pool
    Gymnasium
    Cafeteria
16. Auditorium
17. Pump House
18. Maintainence and Warehouse

Map by Temple University Office of Campus Planning

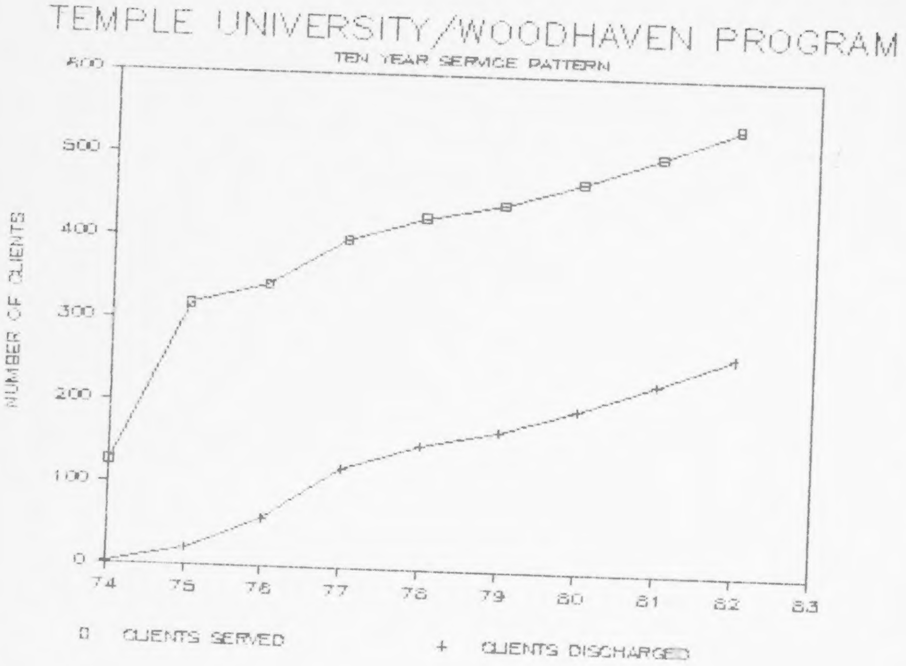
Woodhaven Center
Temple University
2900 Southampton Road
Philadelphia, Pennsylvania 191
telephone: (215) 671-5000

Temple University's Woodhaven Program is recognized as a pioneer in the training of mentally retarded citizens. Less than 25 years ago, the predominant philosophy was basically custodial - keep them quite, fed and, most definitely, out of sight. Barren institutions with ivy-covered walls, located miles from nowhere, were considered the "most humane method" of keeping this population from the consciences of the rest of the world. However, advancements in the last 20 years within the field of behavioral psychology have rendered this old way of thinking, not only archaic, but costly, cruel and impersonal.

Through the use of new behavior modification techniques, even these individuals considered to be the most difficult can be returned to a more meaningful life in an appropriate community setting. An example of how this is accomplished at Woodhaven Center is as follows: From morning wakeup time, in the classroom, in special therapy, in social and athletic/ activities, and in living skills programs, such as eating, cleaning, doing the laundry, our clients successfully strive to meet individualized exit goals within specified time limits.

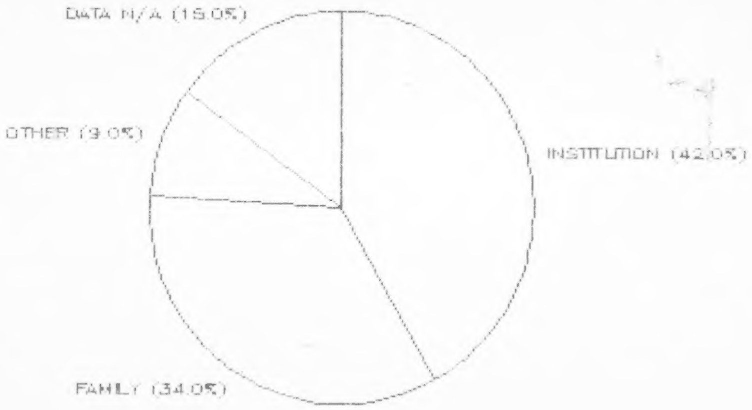
Our Center's main purpose is to use the latest advancements within the field of human service to improve the quality of life for our clients.

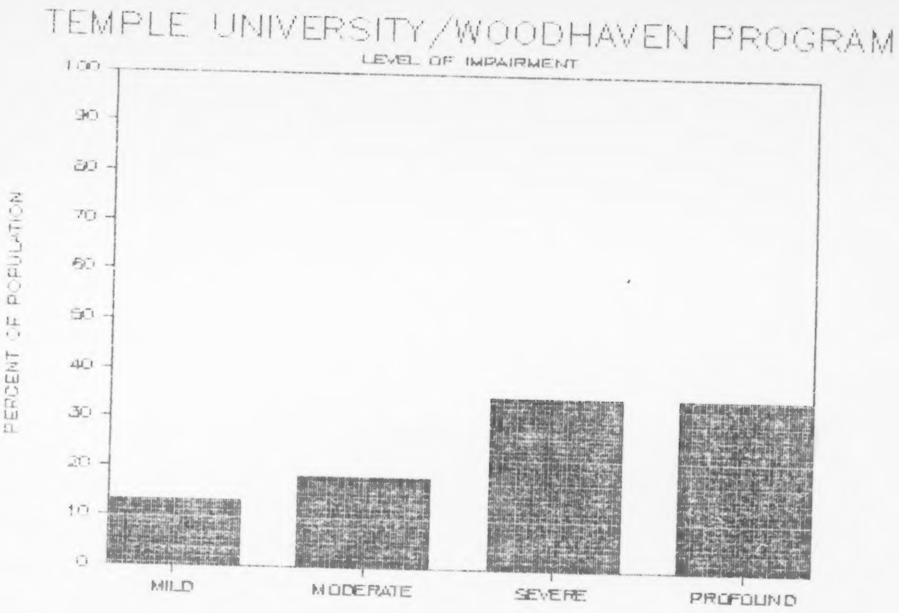
Our experience has shown that even people with severe behavioral problems have responded well to our program, enabling them to prepare for a new life in the community. The kinds of people, their problems and their specific needs which we provide service for are reflected in the following charts.

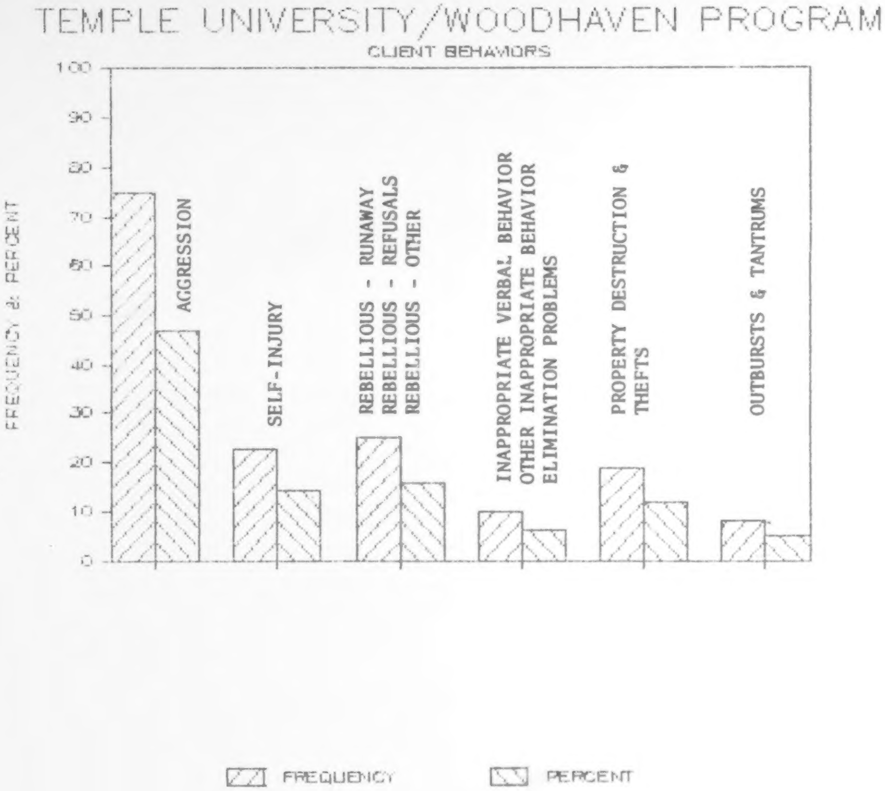

TEMPLE UNIVERSITY/WOODHAVEN PROGRAM
TEN YEAR SERVICE PATTERN
NUMBER OF CLIENTS
600
500
400
300
200
100
0
74
75
76
77
78
79
80
81
82
83
□ CLIENTS SERVED
+ CLIENTS DISCHARGED

TEMPLE UNIVERSITY/WOODHAVEN PROGRAM

PRIOR SETTING OF ADMITTED CLIENTS




TEMPLE UNIVERSITY/WOODHAVEN PROGRAM
LEVEL OF IMPAIRMENT
PERCENT OF POPULATION
100
90
80
70
60
50
40
30
20
10
0
MILD
MODERATE
SEVERE
PROFOUND


TEMPLE UNIVERSITY/WOODHAVEN PROGRAM
CLIENT BEHAVIORS
FREQUENCY & PERCENT
100
90
80
70
60
50
40
30
20
10
0
AGGRESSION
SELF-INJURY
REBELLIOUS - RUNAWAY
REBELLIOUS - REFUSALS
REBELLIOUS - OTHER
INAPPROPRIATE VERBAL BEHAVIOR
OTHER INAPPROPRIATE BEHAVIOR
ELIMINATION PROBLEMS
PROPERTY DESTRUCTION &
THEFTS
OUTBURSTS & TANTRUMS
FREQUENCY
PERCENT

Unfortunately, in many instances, when our clients have reached their exit goals, the present system has not provided adequate fiscal resources to ensure their return to the community. The number of people prepared to leave our Center for a life in a neighborhood setting versus the number of clients actually leaving has been a dismal statistic which is reflected on the chart below.

Year of Admission	Total Admissions	Number of Discharges	In Residence as of 1983	% Still In Residence
1974	126	2	49	39
1975	192	19	99	52
1976	24	37	7	29
1977	56	62	27	48
1978	29	31	16	55
1979	18	19	11	61
1980	28	27	13	46
1981	33	33	22	67
1982	35	34	29	83

Total Number of Admissions since 1974	541
Total Number of Discharges since 1974	264
Percentage of Discharges vs. Admissions	49%
Total Number of People in Residence More than Two Years	209

In reality, this stagnation of our clients' development growth has been not only a cruel hoax to the individuals involved, but a costly waste of taxpayers money. As in any educational process, when the opportunity for learning ceases, skills are lost and maladaptive behaviors often occur. In other words, the money spent to prepare clients for a new life is wasted.

Studies have shown that lifetime maintenance of people in institutions is more costly than well-planned community programs which offer people the opportunity for continuing growth. In addition, once in the community, the cost of required services for the individual is usually less. When there is a long delay in the process of people moving from the institution to the community, as is occurring, savings are not realized. As an example:

COMMUNITY LIVING ARRANGEMENT (CLA) EXPENDITURES AND CLIENT CAPACITY, 1976-1983

	Expenditures			Client Capacity		
Fiscal Year	State Dollars Expended	Increase From Prior Year	% New Money Per Year	Total Slots Available	Increase From Prior Year	% New Slots
1976-77	15,391,325	3,083,044	20%	2,338	269	11.5%
1977-78	21,222,140	5,830,815	27%	2,755	417	15%
1978-79	29,634,000	8,411,860	28%	3,246	491	15%
1979-80	38,943,104	9,309,104	23%	3,507	261	7%
1980-81	52,644,996[3]	13,701,892	26%	3,952	445	11%
1981-82	62,930,143[3]	10,285,147	16%	4,191	239	5.7%
1982-83	68,481,772	5,551,629	8%	4,456	265	5.9%

1) Additional third party funds (SSI, food stamps, etc.) also support the CLA Program but are not shown here.
2) Based on actual slots developed.
3) Represents budget appropriation, not actual expenditures.

Based on Information Received from Pennsylvania Office of Mental Retardation

Few incentives exist to encourage transition of our clients from the institution to the community. Funding changes which are proposed in Act S. 2053 help to facilitate the movement of our special population to a meaningful life in the community, reduce the wasteful process in which institutions are now forced to operate, and provide a more desirable cost-benefit ratio for the taxpayer.

In short, Senators, the Woodhaven experience reflects a radical change in the state-of-the-art of care and opportunity offered mentally retarded citizens.

The hopeless attitude of twenty years ago has been replaced by the commitment to help individuals develop to their fullest potential in community settings.

The law you have before you today could be the dawning of a new age in human services, one in which all citizens in this country will be able to reach their full potential within our society.

Not to modernize laws to be consistent with current thinking as regards mentally retarded people would be as outrageous as refusing students to be taught reading in public schools.

On behalf of the Board of Trustees of Woodhaven Center, I urge you to act expeditiously to enact this much needed law and thank you for the opportunity to share our thinking with you.

TESTIMONY FOR THE WRITTEN RECORD - SENATE BILL S2053
ENTITLED "COMMUNITY AND FAMILY LIVING AMENDMENTS ACT."

We are writing in opposition to Senate Bill S2053. This legislation is a hoax on the public and on those families which have children who require the protective environment of an institution. Practically speaking, if passed, it will result in the closing of every State Institution in the United States, and turn over the care and supervision of these individuals to a group of profit-motivated entrepreneurs. History has shown that this only reduces services and increases cost.

While it is true that there have been problems with some State Institutions, the answer for the profoundly retarded is not to destroy them, but to improve them, as we have done here in Wisconsin. Let's not throw out the baby with the bath water!

Our daughter suffered brain damage due to illness as an infant. Today, at age 29, she presents a physical picture of normality, with the intellectual ability of a first grader, and the emotional stability of a three year old. She is in an institution where she has a nominal job, continuing craft training, and absolute freedom of movement over the 600 acre institutional grounds. If she was in the community, she would be confined to her residence unless she was accompanied everywhere she went. For her, the institution is clearly the "least restrictive" environment.

Although this piece of legislation is sponsored and supported by the National Association of Retarded Citizens, of which we are members, at their recent convention 40% of the membership were opposed to this support. The 60% supporting were obviously people who have never had the experience of caring for a profoundly retarded individual in the community. This group of profoundly retarded represents less than 10% of all the retarded persons, and since their problems are not the same as the less severely handicapped, they should not be lumped together for determining the types of service they need.

May we add that everything that might be accomplished by this legislation is already available through the Community Options Program and the Community Integration Program, thus rendering this bill superfluous and totally unnecessary.

RAZ:jrz

Janis R. Zank

Richard A. Zank

February 16, 1984

Date of Hearing: February 27, 1984
SB2053

TO WHOM IT MAY CONCERN:

I am asking that you do not support the Community and Family Living Amendments Act introduced by Senator John H. Chafee, as I understand this act is intended to gradually shift the federal bill of Medicaid funds from institutional to community based settings. On the surface this appears to be a good idea and in the best interest of mentally retarded people. However, the damage it would do to the institutional programs across the United States would be devastating.

The bill establishes the time frame for phase out of federal Medicaid matching funds for institutional care. The ultimate result would be that State legislatures would be totally responsible for funding institutional programs. I can assure you that in South Dakota the State legislature would not pick up the balance that Medicaid funds have provided. This would result in institutions being closed which some say would be good. I want you to know that I work at an institution for the mentally retarded and have seen the programs and services to the residents of this facility improve tremendously. Most of these improvements can be attributed to our facility becomming certified under Title XIX of the Social Security Program in order to receive Medicaid funds. These Medicaid dollars have allowed us to hire more staff and improve training programs for our clients. The end result is a facility which provides excellent care and training for the clients.

I want you to know that I support the community-based programs which have developed in recent years but I do not think we should attempt to further develop them at the expense of fine institutional programs. Medicaid dollars were originally allocated to institutions in order for them to improve their services and this goal is being achieved. I would ask that you don't dismantle one part of the service delivery system to the mentally retarded in order to satisfy a few idealists who think the system is better off without institutional programs.

I would like you to know that I speak not only as a concerned South Dakota citizen but as a person who has been involved in the delivery of services to mentally retarded people since 1973. I have worked with parents and guardians in an effort to promote community placement for their son or daughter. At the same time I have become increasingly aware of the needs of the residents who remain at this facility. Passage of a bill such as SB2053 would be a terrible blow to the clients who need the services of a facility such as ours. Please vote no on SB2053.

I will be happy to provide the committee with any additional information they would ask for. Thank you!

Randy Joyce

Randy Joyce
Educational Unit Director
Box 410
Redfield State Hospital and School
Redfield, SD 57469

RJ:mak